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**A qualitative exploration of the transmission of knowledge and skills
by specialist stoma care nurses to facilitate the needs of patients
adapting to a newly formed stoma.**

**by
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**A research-based thesis to King's College London
for the Doctorate of Philosophy in Nursing**

**Florence Nightingale School of Nursing and Midwifery
King's College London**

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Abstract

Aim: To identify the knowledge and skills required by the specialist stoma care nurse to facilitate the needs of patients adapting to a newly formed stoma in order to inform specialist nurse education.

Background: Advances in surgical techniques, drug therapies, bowel screening and patient recovery programmes have offered those with colorectal disorders, a potential increased life expectancy and improved disease management. For the specialist nurse, there is the constant challenge to keep abreast of these advances and provide more formal, precise and accurate information, facilitating individualised patient need. In response, an education curriculum needs to foster a comprehensive knowledge base in order to equip and support the nurse to become confident and competent in clinical practice. How knowledge is translated from the classroom into clinical practice is a key feature of this study; in particular the role of the specialist stoma care nurse in facilitating the adaptation of patients following stoma surgery.

Method: A qualitative approach was chosen to fulfil the aim and objectives of this two-staged study. Phase one took a phenomenological approach and phase two a focus group methodology approach. Eight patients were interviewed in phase one. This offered insight into the experiences of living with a newly formed stoma. Vignettes (total 18) were created from the patients' narratives. These were used to stimulate discussion among nurses at the focus groups within phase two of the study. The complexities of translating specialist knowledge and skills among thirty-nine specialist stoma care nurses were explored through one of a series of seven focus groups. The analysis for this study was undertaken in 3 stages; stage 1, thematic analysis of phase 1, stage 2, thematic analysis of phase 2 and stage 3, further analysis of phase 2 using Mayer and Salovey (1997) emotional intelligence theoretical framework.

Findings: Phase one highlighted a variety of challenges faced by patients and recognised their coping strategies as they adapted to a newly formed stoma. Six themes emerged from the

thematic analysis; seeking assurances, permanence versus reversibility of stoma, anticipated stigma, psychological projection, worthwhile sacrifice and sense of achievement.

The thematic analysis of phase two identified five comparable themes; skilled know-how, understanding self, hurdles to accommodate, communication skills and uncertain ground. A further examination through an alternative lens was considered to distil the pedagogy. Mayer and Salovey (1997) emotional intelligence framework guided the third stage of analysis. Five key concepts emerged, forming the essential components to specialist nursing practice; the influence of emotions on critical thinking and clinical decision-making, the use of empathetic and intuitive skills in clinical judgements, the ability to balance true self alongside professional self, the need to foster cognitive activity, good communication and creativity and preserving a conscious awareness of self so to develop personal growth.

Conclusion: Individual experiences of patients adapting to a newly formed stoma evidently differed. Both the challenges faced and coping strategies of the patients were revealed. The specialist stoma care nurse is ideally placed to facilitate meeting the patients' needs as they adapt. The five essential components to specialist practice are identified. Educational strategies for cultivating critical thinking and communication skills, developing self and emotional conscious awareness and nurturing personal growth need to be considered for integration into specialist nurse educational curriculum.

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1. Introduction to the study

1.1 Introduction

The creation of a stoma poses many challenges to patients, as they adapt to this profound life changing event (Deeny and McCrea, 1991, Salter, 1997, Brown and Randle, 2005, Thorpe et al, 2009). Affecting fundamental aspects of quality of life, the experience of living with a stoma is often associated with physical and psychological anxieties (Wade, 1990, Kelly, 1992, Bekkers et al, 1996, Haugen et al, 2006, Danielsen et al, 2013a). Whilst these anxieties may be attributed to the practicalities of stoma care management, studies illustrate how it is not uncommon for patients with newly formed stomas to express feelings of loss, reduced self-esteem and stigma which can disrupt relationships, emotions and produce a whole range of changing attitudes (Kelly, 1992, Price, 1990, Bekkers et al, 1996, Danielsen et al, 2013b).

The process of adaptation is a personal journey involving fluctuations and movements back and forth, as the patient copes with the reactions to the loss of life as it was prior to surgery (Telford et al, 2006). The adaptation process for a patient with a stoma has been illustrated in several studies (Follick et al, 1984, Price, 1990, Kelly, 1992, Bekkers et al, 1996, Simmons et al, 2007, Andersson et al, 2010, Danielsen et al, 2013b, Thorpe et al, 2014), which highlight that adjustment is a gradual process; and that independent stoma care management in isolation is not sufficient to foster adaptation for the patient to return to a full and active life.

A key aspect of the specialist stoma care nurse's role is to facilitate patients' adaptation to stoma surgery. Studies have explored ways in which specialist nurses can support stoma patients and these include: helping patients come to terms with their diagnosis and prognosis

(Baxter and Salter, 2000, White and Hunt, 2002, Haugen et al, 2006), adapting to life with a stoma (Kelly, 1992, Borwell, 1996, Bekkers et al, 1996, Baxter and Salter, 2000, White and Hunt, 2002, Andersson et al, 2010, Danielsen et al, 2013a), teaching practical skills in caring for their stoma (Price, 1990, Borwell, 1996, Haugen et al, 2006, Thorpe et al, 2014) and addressing issues around family, support networks, employment, body image and sexuality (Price, 1990, Borwell, 1996, Baxter and Salter, 2000, White and Hunt, 2002, Andersson et al, 2010, Danielsen et al, 2013b).

Over the years, nurse education has attempted to identify the roles and responsibilities for specialist nursing practice of the nurse. With the help of nursing models, for example, Roy's Adaptation Model (1984) and Orem's Self-care Theory (1980) and studies on communication skills, there is a call on nurses to discuss with patients, lifestyle issues affected by their episode of illness; emphasizing basic patient assessment should include psychological, psychosexual and physical aspects of care. Nurses acknowledge the need to address issues relating to adaptation as part of their specialist role (Reynolds and Magnan, 2005) yet literature implies this is not integrated into everyday nursing practice (Wade, 1990, Kelly, 1992, Booth et al, 1996, Maughan and Clarke, 2001, Reynolds and Magnan, 2005, Notter and Burnard, 2006, Ream et al, 2009). Omitting to do so has a negative impact on the patient's ability to adapt to the disease process and subsequent treatment (Webb and Askham, 1987, Waterhouse and Metcalfe, 1991, Reynolds and Magnan, 2005, Hordern, 2008).

Until recently, the literature has contributed little to inform the precise nature of specialist practice (Leary and Oliver, 2010). Recent financial constraints within the National Health Service (NHS) (Smy et al, 2011) have led to specialist roles being scrutinised, necessitating

specialist nurses to demonstrate their worth (Leary et al 2008, Ream et al, 2009, Leary, 2011, Oddsdóttir and Sveinsdóttir, 2011, Leary et al, 2014). This new evidence has been used to reconfigure specialist nurse service provision and support personal development plans (Norton et al, 2012).

Documents from professional bodies within the United Kingdom (UK) outlining and guiding specialist practice support the view that a specialist nurse is required to exert a higher level of clinical judgement and discretion, which is not delivered by non-specialists during the process of making clinical decisions (NMC, 2006, Williams et al, 2010, RCN, 2012). In essence, they are expected to work to an advanced level of practice. However, the documents omit to advise how this might be achieved. This lack of clarity is compounded by the view point of the Nursing and Midwifery Council (NMC) (2006), that there are nurses who hold job titles that imply an advanced level of knowledge and competence, but who do not possess either of these.

Education plays a vital part in developing skills and knowledge for specialist practice but studies continue to highlight discrepancies between education and the transmission of knowledge into clinical practice (Lewis and Bor, 1994, Booth et al, 1996, Furlong and Smith, 2005, Simmons et al, 2007, Kotronoulas et al, 2009).

Discrepancies between education and knowledge transmission, together with the criticisms of the NMC, indicate a gap between what is espoused as the specialist nurse role and what the role and the specialist nurse concerned delivers to the patient. The phenomenon of the theory-practice gap in nurse education has been subjected to continued analysis and debate

for decades (Jasper 1994, Macleod-Clark et al, 1997, Heslop et al, 2001). This gap may be manifesting itself even more profoundly with the recognition that it is not only nurses' knowledge that is compromised in practice but also their basic professional ideals and values (Maben et al, 2006, Francis, 2013).

Studies exploring nursing roles have highlighted that possessing theoretical skills and competencies does not always reflect emotional ability and for a successful therapeutic relationship, a balance of both are required (Freshwater and Stickley, 2004, Kooker et al, 2007). Other studies have considered personal attributes, attitudes and beliefs (Kautz et al, 1990, Palmer, 1998, Reed et al, 2007) as crucial foundations for a self-aware, empathetic practitioner, equipped to manage their own and others' emotional needs and to work at a more advanced level practitioner (Benner, 1984, Salovey and Mayer, 1990, Freshwater and Stickley, 2004).

A key question arises concerning theoretical knowledge espoused in the education and training of specialist nurses and what is practised by specialist practitioners. This question is explored in this study, focusing on the knowledge and skills of the specialist stoma care nurse in facilitating the adaptation of patients following stoma surgery. Pedagogy refers to the science which studies education as an aspect of the reality of teaching and learning (Chabeli, 2008, Zakari et al, 2014). Its focus includes what is taught and how it is taught (Earle and Myrick, 2009).

1.2 Research aim

Conducted in two phases this study aims to identify the knowledge and skills required by the specialist stoma care nurse to facilitate the needs of patients adapting to a newly formed stoma to inform specialist nurse education.

1.2.1 Research objectives

- To explore the experiences of patients as they adapt to stoma surgery and identify how this differs from one person to another.
- To create vignettes from the patient's experiences, for specialist stoma care nurses to explore.
- To explore the complexities of transmitting specialist knowledge and skills by the specialist stoma care nurse to facilitate the adaptation needs of the patient.
- To identify the pedagogical components required to prepare nurses for specialist stoma care practice.

At the end of this study pedagogical perspective of specialist stoma care practice are conveyed. For the purpose of this study, transmitting and translating specialist knowledge and skills relates to the communications between the nurse and the patient. These terms are used interchangeably throughout.

1.3 Rationale for the study

The rationale for this study derives from an awareness of the diverse and complex issues within stoma care nursing. Having worked in the speciality for over twenty-five years, the researcher has been in a privileged position to not only care for patients undergoing stoma surgery but has also been instrumental in the development of educational programmes for specialist stoma care nursing practice. Patients' experiences and needs are highlighted in the literature and extend knowledge by informing clinical practice. From an educational perspective, there is also a need to inform specialist education and by integrating a pedagogical perspective into the curricula will ensure specialist stoma care nurses are equipped with the knowledge and skills to facilitate the adaption needs of patients.

1.4 Chronology of the research

The study started with a mapping exercise to develop the study context. This included an exploration of the patient experience of stoma surgery and skills required of the specialist stoma care nurse, from the literature. The research question was formulated, together with Phase 1 of the study a research strategy emerged, indicating a qualitative approach. Following ethics approval, the data collection for Phase 1 was completed. These data were analysed using a thematic analysis resulting in the identification of six themes. Vignettes were then created from the patients narratives representing each theme. The vignettes were used to stimulate discussion during the data collection of Phase 2. With the data collection from Phase 2 complete, a thematic analysis was undertaken. Five themes emerged which were comparable to current literature. A further critical appraisal of the literature was undertaken highlighting patients' experiences and perceptions and the efficacy of specialist nursing

practice. This led to the re-examination of the data collected from phase 2 by using the emotional intelligence theoretical framework of Mayer and Salovey (1997). Five essential elements to specialist nursing practice emerged and it is these that contribute to the knowledge informing specialist practice, policy and specialist education.

1.5 Organisation and content of thesis

Contextual information relating to the role of the specialist nurse is discussed in Chapter 2. A critical appraisal exploring a broad range of research into specialist nursing practice and the transmission of knowledge is presented in Chapter 3. Chapter 4 comprises an exploration of pedagogical components of specialist nursing practice. The research design, including the selection of the sample and sampling methods used to meet the aim and objectives, are discussed in Chapter 5. In addition, consideration is given to the methods selected for the data collection; this in turn establishes a foundation for assuring quality and trustworthiness. Chapter 6 explains the conduct of the study. Analysis and findings of the study are interpreted in Chapter 7, followed by discussion and implications for practice, policy and education in Chapter 8. Chapter 9 offers a personal reflection and reflexivity of this qualitative study. And finally Chapter 10 presents the conclusion, critique of the research method, study limitations and the implications for nursing practice as well as recommendations for future research.

2. Context of specialist nursing practice

2.1 Introduction

Advances in surgical techniques, drug therapies, bowel screening and patient recovery programmes have offered those with colorectal disorders an increased life expectancy and improved disease management. For the specialist nurse, there is the constant challenge to keep abreast of these advances and provide more formal, precise and accurate information, facilitating individualised patient need (Olsson et al, 2002, Mottram, 2011). In response, education curricula need to foster a comprehensive knowledge base in order to equip and support the nurse to become confident and competent in clinical practice. How knowledge is transmitted through clinical-based learning is a key feature of this study, in particular a pedagogical perspective of specialist education that will equip the specialist stoma care nurse with skills to facilitate the adaptation needs of patients following stoma surgery.

This chapter examines the context of specialist nursing practice. This analysis leads to a detailed review of the present understandings of specialist practice within the United Kingdom (UK) and in defining the roles and responsibilities of specialist practice will lead to the clarification of the key features to support and justify this study. Initially a brief overview of current specialist stoma care nursing will be given.

The term specialist stoma care nurse refers to all specialist stoma care nurses in the UK, as job titles, roles and responsibilities differ according to local healthcare needs (Stansfield et al, 2011). The terms specialists, advanced and expert are all used within the same context

throughout the literature inferring they are intrinsically linked. For this reason these terms will be used interchangeably throughout this study.

2.2 The patient with a stoma

Formation of a stoma is a well-recognised surgical procedure in the treatment of various diseases including: cancer, inflammatory bowel disease, diverticulitis, incontinence and trauma (Williams et al, 2010). Estimations suggest there are 102,000 people with a stoma in the UK (Elcoat and Frost, 2010), with approximately 21,000 new stomas formed every year (Elcoat and Frost, 2010); the majority being temporary. Described as an artificial opening (Porrett and McGrath, 2005), a stoma is created surgically by passing a section of bowel through a small cut in the abdominal wall and suturing it securely in place. This allows the flow of faeces and/or urine to be redirected into a stoma appliance positioned on the front of the abdomen. Central to this study are patients with faecal output stomas. Urinary output stomas are not included as procedures are substantially different from faecal output stomas (Klopp, 1990).

The literature highlights that patients with stomas face many problems, both physically and psychologically. These may include leaking stoma appliances, sore peristomal skin, ballooning of stoma appliances, unpredictable bowel function, odour and uncontrollable noisy flatus (Follick et al, 1984, Thomas et al, 1987a, Thomas et al, 1987b, Wade, 1990, Kelly, 1992, Pieper et al, 1996, Nugent et al, 1999, Persson and Hellstrom, 2002, White and Hunt, 2002, Clarke et al, 2004, Notter and Burnard, 2006, Borwell, 2006, Krouse et al, 2007, Andersson et al, 2010, Chao et al, 2010). These problems can lead to anxiety and embarrassment and can directly

affect the person's lifestyle (Kelly, 1992, Borwell, 2006, Chao et al, 2010, Haugen et al 2006, Danielsen et al, 2013b).

2.2.1 Current colorectal surgery and nursing practice

The introduction of bowel screening programmes, including diagnostic and therapeutic surveillance, has resulted in earlier and more rapid diagnoses of many conditions. As a result there is a greater likelihood of either undergoing reconstructive surgery, resulting in a temporary stoma or avoiding stoma surgery altogether (Pachler and Wille-Jørgensen, 2012). From a physiological perspective, closure of a temporary stoma is determined once the bowel at the surgical anastomosis has healed or there is no evidence of inflammation or oedema (van de Pavoordt et al, 1987). Temporary stomas have reportedly more psychological disturbances than permanent stomas as the patient has constant feelings of insecurity until the stoma is eventually reversed (Taylor and Varma, 2012, Danielsen et al, 2013a).

Colorectal surgery was traditionally associated with significant morbidity and prolonged hospital stay (Bokey et al, 1995, Abraham et al, 2004) and as a result the concept of fast track or rapid recovery was introduced (Kehlet and Mogensen, 1999) with the purpose of improving post-operative recovery rates and reducing the length of hospital stay. Such programmes are now replacing more conventional approaches to surgical care (Jeff and Taylor, 2014). Commonly referred to as the enhanced recovery programme or enhanced recovery after surgery (ERAS), it consists of a number of strategies to ensure the patient's condition is optimised at all phases of the pre, peri and post-operative recovery. ERAS protocols include reduced fasting, pre-operative carbohydrate loading and whole body warming, avoiding

bowel preparation, nasogastric tubes and drains, adapted anaesthesia and pain management, laparoscopic surgery and intraoperative fluid therapy (Mitchell, 2011, Bernard and Foss, 2014, Jakobsson et al, 2014). These approaches lead to earlier postoperative mobilisation and reintroduction of oral intake and a shortening of the average hospital stay from ten days to five (Abraham and Albayati, 2011).

Systematic reviews have demonstrated vast improvements in reducing surgical morbidity rates and length of hospital stay within ERAS programmes (Vlug et al, 2009, Bartels et al, 2010, Aalbers et al, 2011). Other studies reflect experiences of patients, portraying both positive and negative aspects of the programme by suggesting a greater patient autonomy and empowerment (Taylor and Burch, 2011, Aasa et al, 2013) whilst also reporting post discharge vulnerability, lack of support and information provision as areas of concern (Mitchell, 2011, Taylor and Burch, 2011, Lithner et al, 2012). Jakobsson et al (2014) demonstrated varying recovery processes amongst a similar sample of patients undergoing colorectal surgery, suggesting long-term support was required from specialist practitioners to facilitate their return to wellbeing.

The move from conventional surgical care to ERAS requires a multidisciplinary approach (Jeff and Taylor, 2014) heightening the importance of communication and provision of information. This is not only to ensure ERAS protocols are adhered to but also to ensure the patient has the correct information to give informed consent. Given the characteristics of fast-tracking a patient through a recovery programme implies the delivery of information to patients is condensed. From the specialist nurses' perspective, possessing knowledge and

clinical skills to gauge patients need will allow information to be tailored and transmitted in a manner that is appropriate for the patient to comprehend.

2.2.2 Adaptation to stoma surgery

The ability to adapt is seen as an intricate process with many changes until the individual feels able to come to terms with, and accept their new situation (Olsson et al, 2002, Newell, 1999, Krohne and Slangen, 2005, Telford et al, 2006, Chao, 2010). Adaptation occurs over time (Patterson, et al 1993) and may take months or even years (Ganz, 1990). Adaptation has been described as “an energy requiring process to return to a state of normality and wholeness” (Allvin et al, 2007, p557). Following surgery, adaptation has been characterized by the ability to regain control over physical, psychological and social functioning resulting in a return to level of independency/dependency in activities of daily living as seen prior to the surgical intervention (Salter, 1997, Olsson et al 2002, Krohne and Slangen, 2005, Allvin et al, 2007). This infers adaptation is informed by the individuals’ former state of health and what they might class as normal for them.

There are two models associated with illness and adaptation that might reflect how the patient with newly formed stoma begins to adjust; Gerhardt’s (1989) negotiation model and Becker’s (1963) crisis model. The negotiation model (Gerhardt, 1989) focuses on the gradual loss of normal self during chronic illness. Patients with long term conditions such as Crohns disease or Ulcerative colitis may experience a gradual deterioration in their condition; it might only be slight but is generally constant. As a consequence any further degree of deterioration in their ill-health is adapted to and becomes the new norm. In this instance stoma surgery can

offer the patient instant well-being and might be viewed as less significant than maybe those within the crisis model (Becker, 1963).

Becker's (1963) approach of the crisis model relates to the sudden change in a person's identity. Rapid diagnoses of bowel cancer through bowel screening programmes or unexpected trauma to the bowel, for example, perforation, resulting in stoma formation will bring about a sudden change in the patients identity, presenting them with little preparation for life with a stoma. This sudden change in identity might draw attention to the difficulties experienced by the patients as highlighted by the literature, potentially leading them to struggle to adapt.

Barclay-Goddard et al (2012, p214) described a 'response shift' where individuals begin to accommodate their chronic illness through the development of personal goals and the re-evaluation of self. Such personal goals can help a patient with a new stoma adapt. As the patient overcomes their problems, their confidence grows and the intensity of the problem starts to decline and gradually they begin to see their recovery improving. Such outcomes enable patients to consider that they are disease free, allowing them to reflect upon personal fulfilment, find meaningful pursuits in life and have a greater appreciation of life (Olsson et al, 2002). It should be noted, however, that prolonged problems and stoma complications are known to lengthen the process of adapting to a new stoma (Cottam et al, 2007).

Adaptation for patients with a stoma is seen as a complex relationship between acceptance, social interaction and stoma care self-efficacy (Simmons et al, 2007). Each patient with a new stoma will have complex and individually experienced social circumstances, identity and

coping strategies, sexuality and spiritual beliefs. All these factors, in addition to stoma problems, can influence the experience of living with a stoma and how patients adapt to their stoma early on and whilst it is present (Thorpe et al, 2014). In addition to the practicalities of stoma care, a patient with a new stoma needs to come to terms with the anxieties and concerns towards self-integrity such as body image, self-esteem, attractiveness, sexuality and fertility, and disclosure (Follick et al, 1984, Thomas et al, 1987a, Thomas et al, 1987b, Price 1990, Pieper et al, 1996, Salter, 1997, Cook, 1999a, Simmons et al, 2007, Thorpe et al, 2009). This infers that for some, stoma surgery brings immense changes to them as a person, affecting their innermost feelings, beyond anything they may have experienced before.

The initial three months post stoma surgery are described as the most challenging to patients as they come to terms the profound changes stoma surgery brings (Thomas et al, 1987a, Thomas et al, 1987b, Wade 1990, Kelly, 1992, White and Hunt, 2002, Krouse et al, 2007). Individual adaptation outcomes will vary from person to person depending on different attributes including personal expectations, level of emotional appraisal, beliefs, time and prevalence of complications during the recovery period (Ganz, 1990). Depending on the disease trajectory, adaptation for some may feel like moving between two extremes: feeling ill and feeling well (Olsson et al, 2002).

Personal control has been noted to be an important feature of adaptation following bowel surgery (Galloway and Graydon, 1996, McVey et al 2001, Cooper et al, 2010). Of these studies McVey et al (2001) is the only study to have noted that stoma surgery for colorectal cancer attributed to lowered personal control. Through its longitudinal approach, this study demonstrated that perceptions of uncertainty remained influential throughout the patients'

journey towards adaptation. Such perceptions included an unclear future, physical discomfort, unpredictable bowel function, poor outcomes from surgery and a lack of understanding through poor information giving. The causes related to lowered personal control as identified by McVey et al (2001) stress the importance for specialist nurses to possess appropriate knowledge and skills to facilitate the patients' adaptation needs.

Bekkers et al (1997) used the validated Psychosocial Adjustment to Illness Scale (PAIS-SR) in a 4-year follow up study comparing adjustment and survival in patients undergoing surgery for malignant and non-malignant bowel conditions. One hundred and twenty-three participants entered the study with 68 completing the 4-year follow up. For 28 of these participants', bowel surgery had resulted in stoma formation. The PAIS-SR consists of 5 domains and 33 items; each measured using a 4-point scale of adjustment (0-3). Adjustment was assessed at four points during the 4-year follow-up period; 1 week, 4 months, 1 year and 4 years. High scores referred to poor psychological adjustment. Their findings indicated that at the initial assessments those participants with a stoma experienced significant psychosocial problems, in particular, sexuality and returning work. At the third and fourth assessment points adjustment scores did not differ between those with or without a stoma. This study mirrored earlier work by Wade (1990) who, whilst exploring the efficacy of the specialist stoma care nurse, reported anxiety and depression following stoma surgery was associated with higher death risk and later work by Olsson et al (2002) suggested that the first three months following surgery can be characterised by feelings of loneliness and disappointment. These studies indicate a need for long term follow-up where specialist nurses possess the skills and ability to recognise patients who might be experiencing a delay in their adaptation towards the stoma.

Those recovering from stoma surgery are likely to have some degree of need, either practical or psychological. If these are adequately addressed they can promote self-help, thus reducing dependency on others. McVey et al (2001) noted the availability of support at this time to be of immense importance, in hospital and at home, for the patient with a new stoma; in particular, access to emotional support to improve self-efficacy perceptions by the patient. However, in a study regarding post-operative needs of patients with colorectal cancer, it was highlighted that despite the presence of nursing and medical support some patients felt they were left to make decisions regarding their health on their own (Taylor, 2001). Knowing about and making sense of patients' emotional and physical needs is far from straightforward. The specialist stoma care nurse plays an important role in this aspect of the recovery of patients, assessing and facilitating their physical and psychological needs as the patient learns to adapt and begin to regain their optimal level of wellbeing.

2.2.3 Measuring adaptation to a stoma

The literature presented in this analysis has defined the adaptation to a stoma as the overall impact of the stoma on psychological, social and sexual functioning as perceived by the patient. Assessing adaptation needs of a patient with a stoma therefore necessitates the ability to accurately assess and recognise the patient experiencing difficulties in any of these areas. Several validated and non-validated health-related instruments are available for measuring adaptation. Three such instruments have been developed by researchers specifically to measure study outcomes relating to adaptation in patients with stomas. These are The Ostomy Adjustment Scale (OAS) (Olbrisch, 1983), the Stoma Self-Efficacy Scale (SCSES) (Bekkers et al 1996) and the Ostomy Adjustment Inventory-23 (OAI-23) (Simmons et al, 2009).

The OAS (Olbrisch, 1983) consists of 34 items specifically to measure psychological and social adjustment in patients living with a stoma. Initially Burckhardt (1990) implied further evidence was needed to confirm the tools reliability and validity, however latterly, Simmons et al (2007) reported the scale to be reliable if all 34 items within scale are used but also observed that the tool offered little consideration to the varying nature of adjustment in relation to stoma type. Bekkers et al (1996) developed the Stoma Self-Efficacy Scale (SCSES) using two components to assess adaptation; self and social efficacy. This instrument has the ability to measure individual perceptions relating to the ability to manage their stoma in order to minimize adverse outcomes. The scale consists of 22 items measured by the use of a 5 point Likert scale (1 = not confident, 5 = extremely confident). An accumulative score is therefore obtained with higher scores indicating greater levels of confidence in stoma care and living with a stoma. Highlighting the flexibility of the measuring tool, the authors suggest the two components can be used separately or in association with each other.

More recently, Simmons et al (2009) developed the OAI-23 instrument to measure psychological adjustment. This 23 item scale is divided into four subscales; acceptance, anxious preoccupation, social engagement and anger. This instrument is noted to offer ongoing assessment of patients' adaptation to stoma surgery regardless of stoma type.

These three tools have been developed for research purposes only and as yet have not been evaluated for use in clinical practice; therefore confirmation to the instruments validity and reliability is unsubstantiated. There is currently no evidence to indicate such tools are being used to guide specialist stoma care nurses in addressing adaptation issues of patients. These tools clearly measure adaptation specifically for stoma patients and would complement

specialist stoma care nursing practice, if used as an aid memoire, supporting clinical judgements and informing decision-making. Whilst these tools are seemingly underutilised, the specialist stoma care nurse is dependent upon their knowledge, skills, experience and abilities to facilitate the adaptation needs of the patient with a stoma. How specialist stoma care nurses transmit their specialist knowledge and skills to facilitate patient need is a key feature of this study and therefore leads onto a more in-depth consideration of specialist nursing practice.

2.3 What is specialist nursing practice?

The specialist nurses are nurses who through study and supervised clinical practice at graduate level have become an expert in a defined area of knowledge and practice (Bingle and Davidson, 2014). Specialist expertise will include leadership and the management of a patient caseload, where they provide a patient-focused approach to diagnosis, holistic care planning, treatment provisions, follow up, ongoing management and continuity of care (Wilson-Barnett and Beech, 1994, Bousfield, 1997, McCreddie, 2001, National Cancer Action Team, 2010, Farrell et al, 2011, Hopkins and Irvine, 2012, RCN, 2009b, RCN, 2013a). Expertise is evident when the nurse is able to respond to complex situations with ease, precision and fluidity which inspire confidence in others (Scholes, 2006).

The concept of specialist nursing practice is over 100 years old (Vidall et al, 2011) and has evolved in response to healthcare needs and to the changing context of nursing care (Dury et al, 2014). Until recently the literature has contributed little to inform the precise nature of specialist practice (Leary and Oliver, 2010, Begley et al, 2013) inferring levels of expertise and

competence cannot be verified (Daly and Carnwall, 2003). Debate regarding the role continues (NMC, 2006, RCN, 2010a, RCN, 2013a). Some suggest this is a fruitful debate as it ensures the essence of nursing is not lost (Leary, 2011) but for others there is a feeling of erosion within specialist practice, leading to the blurring of boundaries with other healthcare roles such as doctors and other allied healthcare professionals (Longley et al, 2007, Donald et al, 2010, Fulton, 2014).

Specialist practice has been described as an extension of generalised practice (Castledine, 2004). This suggests that a nurse specialising in any clinical area develops more knowledge and skill in relation to that particular area. This is based on the fundamental aspects of nursing, which as an individual, have been transferred from generalised practice, into and across, the specialist clinical area. The emphasis of the specialist nurse's speciality can be disease specific (Specialist Inflammatory Bowel Disease Nurse), related to an aspect of patient care (Specialist Paediatric Nurse), an area of care (Specialist Stoma Care Nurse) or treatment category (Specialist Chemotherapy Nurse). Whilst these titles indicate the narrowed focus of the knowledge and skills appropriate for the role, there is little indication as to the ability of the individual to perform at a specialist level.

Whilst scoping the literature for this analysis it was noted that there is a considerable body of literature evaluating specialist nursing practice. The vast nature of literature has led to a wide range of interpretations regarding levels of practice, differentiating roles, responsibilities, titles, clinical activities and expected impacts within specialist clinical practice (Farrell et al, 2011, Dury et al, 2014). Potentially this has misled specialist practice, within specialist practice

itself, other healthcare colleagues, commissioning bodies and stakeholders, organisations and regulators.

Five potentially relevant systematic reviews from the renowned UK Cochrane Centre (www.cochrane.org/cochrane-reviews/) were identified. These reviews varied in the way the authors approached the topic but the primary focus was an examination of the activity and outcome of the clinical nurse specialist role whilst working within a variety of clinical specialities; breast care (Cruickshank et al, 2008), diabetes mellitus (Loveman et al 2003), bronchiectasis (French et al, 2003), inflammatory bowel disease (Belling et al, 2009) and gynaecological malignancy (Flynn et al, 2014).

In very general terms, these systematic reviews found limited evidence for the effectiveness of specialist nurses in relation to rehabilitative care although Belling et al, (2009) pointed out that this is a particularly difficult area to capture. This was sometimes because few studies were found that met the inclusion criteria, as in the reviews of bronchiectasis (French et al, 2003), and inflammatory bowel disease (Belling et al, 2009) but might also indicate a lack in ability of specialist nurses to facilitate this need. Some reviews attempted to evaluate specialist nursing services as a whole (French et al, 2003, Loveman et al, 2003, Cruickshank et al, 2008), while others evaluated specific interventions performed by specialist nurses (Flynn et al, 2014, Belling et al, 2009). Amongst those reviews evaluating the specialist service as a whole, no difference in patient survival or morbidity, when comparing specialist nursing or medical practice was reported (French et al, 2003, Loveman et al, 2003, Cruickshank et al, 2008). This, according to Loveman et al (2003 p9) makes it difficult to establish precisely what constitutes 'the active ingredient' of specialist practice, when evaluating the role.

2.3.1 Role descriptors of the specialist nursing practice

Much of the literature regarding specialist, advanced and expert practice is provided by international literature predominately from the USA, Canada and Australia. This literature is noted to have had greatly influenced the UK's interpretation of specialist practice as we constantly strive to understand and appreciate the multifaceted nature of the role (Bousfield, 1997, Ball, 2005, Leary et al, 2008, Por, 2008, Farrell et al, 2011, Vidall et al, 2011, Hopkins and Irvine, 2012, Sephton and Kemp, 2013, Sorrell, 2013).

Role is defined as a set of expected actions of an individual that is characterized by a pattern of behaviour in a given social setting (Bingle and Davidson 2014). The specialist role is a practical one and portrayed in nursing through a set of clinical components (Hamric, 1989, International Council of Nurses, 2008, Fulton, 2014). The role descriptors of the specialist nurse are often described as a combination of five components; clinical, education, research, change agent and consultation (Hamric, 1989). Validating this, the NMC (2006) maintained specialist nursing practice engaged in four key themes: advanced practice, facilitating learning, leadership and management, and research.

The Royal College of Nursing (RCN) (2013a) recognise a plethora of titles and clinical settings in which specialist practice exists and in the 2010 census of cancer specialists, researchers found that among 2,000 nurses, there were 48 different job titles with varying roles (Trevatt and Leary, 2010). It is difficult to determine whether this is the diversity of the disease associated with the speciality or the characteristics and skills of the specialist nurses themselves.

This wide variation in job title and role is the likely cause of lack of clarity, leading to misperceptions surrounding roles and responsibilities (Bousfield, 1997, Daly and Cornwall, 2003, Osbourne et al, 2010, Donald et al, 2010, Farrell et al, 2011, Vidall et al, 2011, Hopkins and Irvine, 2012, RCN, 2012, Sephton and Kemp, 2013). The benefits of specialist practice to patients and Trusts have been indicated (RCN, 2010b) but the lack of consensus on title and role definition leaves specialist practice with no strong identity (NCAT, 2010, Leary, 2011, Hopkins and Irvine, 2012, Sephton and Kemp, 2013). This can only lead to a further lack of understanding of the role amongst patients, other healthcare professionals and commissioning bodies with regards what skills and experience are required to have the official title of specialist nurse.

Bousfield (1997) described specialist nurses to be among the most motivated, intelligent and hardworking of nurses. Nonetheless, it has been documented that specialist nurses have difficulty maintaining their role, regardless of educational preparation, role definition and set competencies (Farrell et al, 2011, Vidall et al, 2011, Hopkins and Irvine, 2012). Role ambiguity, isolation and role strain with reduced job satisfaction are some of the problems identified (McCreaddie, 2001, Vidall et al, 2011). Hamric et al (2014) demonstrated the need for a consistent definition of core competencies in order to standardise education and the need for the advanced practitioner to practice these competencies, in order to demonstrate the value-added component they bring to patient care. There are however potential shortcomings as there are nurses who hold job titles that imply an advanced level of knowledge and competence but who possess neither of these (NMC, 2006). This therefore leaves nurse education with the challenging task of equipping nurses with the skills to perform at the level required, when it is unclear as to what is essentially required. The development of a

pedagogical perspective of specialist practice would offer some clarification and is an intention of this study.

2.3.2 Organizational perspective of specialist practice

Variation in specialist roles and responsibilities has previously been highlighted (Reed et al, 2007, Ream et al, 2009, Norton et al, 2012, Leary et al, 2014). It would also appear that titles and roles vary not only within organizational and clinical settings but also within the same speciality (Reed et al, 2007, Ream et al, 2009, Norton et al 2012, Leary et al, 2014). Bryant-Lukosius (2004) places part of the responsibility for this on healthcare organizations, suggesting new specialist roles that are created to resolve specific health care issues are reactive rather than proactive; signifying a lack of understanding. With no clear understanding organizations fail to define the new specialist role, are unable to set well-defined achievable goals or consider the organizations priorities for improving the health care issue. An example of this is the current implementation of the dementia nurse specialist role (Griffiths et al, 2015) in response to the recent Government's policy paper (DH, 2015). If implementation varies there is an increased risk to the lack in role clarity where inconsistent expectations might contribute to role conflict, role overload and variable stakeholder acceptance (Bryant-Lukosius, 2004). This lack of role clarity was also recognised within the other reviews as variations between different specialists, differing range of interventions, location of post holder governing service provision and organisational constraints within the role were reported (French et al, 2003, Cruickshank et al, 2008, Flynn et al, 2014, Belling et al, 2009).

With ongoing changes to organizational culture and delivery of care further confusion for the specialist nurse is inevitable and can lead to resistance, as key stakeholders understand how the changes might affect their roles and responsibilities (Jeff and Taylor, 2014). Care and service provision provided by specialist nurses are often considered to be expensive and therefore the specialist nurse needs to develop skills and competencies to justify and secure their future. McCorkell et al (2015, p227) believe specialist nurses need to develop 'a level of business acumen' that will put them in stronger positions to defend their services.

Current financial constraints have led to further scrutiny of the specialist nurses role, highlighting the need for nurses to demonstrate their worth (Leary et al, 2008, Oddsdóttir and Sveinsdóttir, 2011, Norton et al , 2012, Leary et al, 2014). Such studies explored real-time activities of specialist practice indicating frustrations among specialist nurses as they tried to balance role expectations with the realities of clinical workload. This new evidence has been useful in reconfiguring specialist nurse provision. However, not all aspects are helpful as the fundamental aspects of the role cannot necessarily be measured (Trevatt and Leary, 2010); 'it's not so much the direct care provided but measuring indirect care proves a little more difficult' (Leary, 2011, p46). McCorkell et al (2015) also take into account that specialist nurses can only demonstrate their worth if they have the tools to do so. This cross sectional study explored issues encountered by specialist nurses, highlighting insufficient resources were made available to them in order to achieve their role entirely; this included administration support and restricted opportunities for learning and development.

2.3.3 The regulation of specialist nursing practice

Advanced nursing practice within the UK is said to have emerged and progressed as a result of the reduction to junior doctors' hours, overcrowded emergency departments and a growth in specialist areas of nursing such as mental health, elderly care, renal care and oncology (Ball, 2005, Lowe et al, 2011, Hopkins and Irvine, 2012, Begley et al, 2013). In addition, several government white papers have encouraged the evolving role of the advanced and specialist practitioner (DH, 1997, DH, 1999, DH, 2000, DH, 2002, DH, 2006, DH, 2010). The most recent sets the political vision and principles for patient care in the coming years (DH, 2010). This puts patients at the heart of services, focusing on clinical outcomes and empowering healthcare professionals.

Influenced by these government papers, the NMC, as the professional body, is said to guide nursing and in particular specialist nursing practice. The emphasis for the NMC (2015) is to produce individuals that are fit to practice, that is to say they have the skills, knowledge and good character to do their job safely and effectively. Guidance for specialist practice has not been up-dated, nevertheless, the Nursing and Midwifery Council (2006, p8) considers a specialist practitioner to be an individual who is working beyond their initial registration and define the role as 'a registered nurse who has command of an expert knowledge base and clinical competence, is able to make complex clinical decisions using expert clinical judgement, is an essential member of an interdependent health care team and whose role is determined by the context in which s/he practises', signifying an advanced level of nursing practice.

The NMC have not updated their standards for specialist education and practice since 2001 (NMC, 2001) and as a consequence specialist nursing has relied on guidance from the National Institute for Clinical Excellence (NICE) and its union membership organisation the RCN, for guiding roles and responsibilities, education and competencies of specialist practice. This lack of guidance by the NMC has led to further disparity. However, since the Department of Health (2010) recommended that the NMC regulate advanced and specialist nursing practice the launch of the New Code and re-validation (NMC, 2015) is currently being implemented. The New Code (NMC, 2015) proposes to build upon existing foundations of good nursing and midwifery practice and offer opportunities to acknowledge and regulate the wider aspects of nursing and midwifery roles ensuring appropriate competencies have been acquired and are recorded as such on the NMC register. It is in its infancy but will take effect as of April 2016 (NMC, 2015). The re-validation process includes all nursing and midwifery professionals and requires them to engage in demonstrating that as an individual they practice safely and effectively. One of the key features of the re-validation process is to reflect upon professional standards of practice as stipulated by the NMC (2015). If the roles and responsibilities of specialist and advanced practice continue to extend re-validation will support this ensuring clinically competencies are maintained and individuals are keeping professionally up-to-date which can only enhance to the safeguarding of the patient.

2.3.4 The competencies of specialist nursing practice

Competencies are described as underlying characteristics of individuals that result in effective performance (RCN, 2009a) and are defined as a 'state of having the knowledge, judgement, skill, energy, experience and motivation required to respond adequately to the demands of

one's professional responsibilities' (Roach, 1992, p61). A collection of competencies are said to represent a competency framework (RCN, 2009b). Indeed, a national competency for specialist practice is consistent with recommendations from the recent Francis Report (2013) which demanded skills and competencies to be standard in any clinical setting.

Competency and skills frameworks are essential for scope of practice, entry level education and qualification (Furlong and Smith, 2005, Phillips, 2007) and help to facilitate lifelong learning, provide a benchmark standard and assist individuals to review their strengths and weaknesses to highlight education and training needs (RCN, 2009b, Stewart and Rae, 2012). For some they are therefore a vital component to nursing practice; ensuring patient safety (Mason, 2011). However, there is debate as to what constitutes skills and competencies and their relevance to educational curricula development for the advanced nurse practitioner and unless skills and competencies are viewed in a broader perspective they can seem insignificant (Freshwater and Stickley, 2004, Sephton and Kemp, 2013).

The RCN (2009b, p8) stated that beyond initial registration, a specialist nurse is deemed competent 'when (s)he possesses the skills and abilities required for lawful, safe and effective professional practice without direct supervision' and considered this to be the minimal level required for an individual to practice effectively. The NMC (2006, p1) were more explicit, stating 'only nurses who have achieved the competencies set by the Nursing and Midwifery Council for a registered advanced nurse practitioner are permitted to use the title advanced nurse practitioner', with an ultimate goal of ensuring each patient's treatment and care is based on best practice. If specialist nurses are to remain credible, a clear outline for current

advanced level of practice is needed with clear guidance for the level of experience or aptitude required, i.e. a broader perspective.

One of the ways of thinking regarding competence in terms of levels of performance relates to a key element of Benner's (1984) theory about nursing. Benner (1984) proposed that the practitioner begins as a novice and progresses through various stages of development to become an expert. In this circumstance, a beginner may be assessed as competent for novice-level practice and incompetent for the higher levels. The concept that one is either competent or not ignores the complicated realities of holistic patient care, the environment for care and many other factors that can all have an effect on how the practitioner performs. Essentially working at an advanced level of practice means all these variables should be factored into patient care planning and delivery.

A recent RCN (2013b) publication adapted Benner's (1984) 'novice to expert' concept to develop a basis of competencies for specialist endocrine nurses. Within the document the authors' acknowledged they would expect nurses new to the specialty to have reached a competent level within 6 months and that an endocrine nurse functioning at 'expert' level is likely to have had some years of experience in the specialty and be working autonomously. It could therefore be concluded that some nurses could be 'experts' in a particular disease area whilst only achieving a 'competent' level in another area, indicating specialist knowledge and skills are acquired through time.

The NHS Knowledge and Skills Framework (NHS KSF) that forms a key part of Agenda for Change (DH, 2004) was developed to support career progression and personal development

and indeed assessed competency and since, has been integrated into core competencies for registered nurses by the RCN (2009b, 2012). The framework defined and described the level of knowledge and skill NHS staff required to deliver quality services (RCN, 2009b, Stewart and Rae, 2012). It provides a single consistent comprehensive and explicit framework on which to base the review and development of all staff (DH, 2004). The NHS KSF is made up of 30 dimensions (See Table 2.1).

Table 2.1 – *The NHS KSF (DH, 2004)*

The NHS KSF	
Core dimensions (all six relevant to every NHS post)	Specific dimensions (24 grouped into 4 themes and not relevant to all NHS posts)
Communication	
Personal and people development	Health and well-being
Health, safety and security	Estates and facilities
Service improvement	Information and knowledge
Quality	General
Equality and diversity	

These dimensions identify broad functions that are required by the NHS to ensure the provision of high quality of patient care and services. More specific knowledge and skills for specialist practice are illustrated in Table 2.2.

The main focus for the NHS KSF is on the application of knowledge and skills and therefore does not describe the precise knowledge and skills required for an individual to become a specialist stoma care nurse. Since the introduction of the framework, its utilization has improved (Stewart and Rae, 2012), commitment and engagement with the NHS KSF was

reported to be lacking (Brown et al, 2010). Challenges such as not being user-friendly or too complex seemingly restricted its continued use (Berridge et al, 2007, Brown et al, 2010).

Table 2.2 – Knowledge and Skills Framework for Specialist Nurses (adapted from DH, 2004)

KSF Dimensions	Required for post	Level for post			
Core dimensions		1	2	3	4
Communication	X				X
Personal and people development	X				X
Health, safety and security	X			X	
Service improvement	X			X	
Quality	X			X	
Equality and diversity	X			X	
Specific dimensions					
IK2 Information collection and analysis	X			X	
IK3 Knowledge and information resources	X			X	
GI Learning and development	X				X
G7 Capacity and capability	X			X	
<i>X indicates Yes</i>					

The framework was designed to aid performance and appraisal but could also be used to aid recruitment and retention (RCN, 2009b). It has also been suggested that it can assist educational institutes to plan and deliver educational programmes and as a result meet the demands of patient care more effectively (Stewart and Rae, 2012). However as it has not been widely accepted by healthcare institutions within the UK it is difficult to see its worth as an effective competency framework again leaving no satisfactory process for assuring specialist practitioners have the appropriate skill set to practice at an appropriate level.

Ultimately, for a nurse to provide safe, good quality nursing care a level of competent practice needs to be maintained and this is generally achieved by nurses engaging in continuing

personal and professional development. Benner (1984) noted that the transition from a novice to an expert practitioner is not straightforward. Learning styles, experiences and personal attributes impact greatly on an individual's growth and development and therefore require some consideration. Whilst competence is an important concept, there are several approaches to its understanding. Some argue that it is the ability to perform a task or possess the attributes critical to be an effective practitioner (Eraut, 1998, Watson et al, 2002, Taskase and Teraoka, 2011) whilst others claim it as a more complex combination of knowledge, skills, values, inspirations and personal traits (Roach, 1992, Carraccio et al, 2002, Taskase et al, 2015). In this sense a competency can also be seen as the way someone performs; not in a sense as to whether they tick a box but more their ability to think, to question and to reason.

Recognition of this complexity has encouraged a different way of considering competencies, meaning that it could differentiate between an exceptional or mediocre practitioner (Freshwater and Stickley, 2004). This suggests that the specialist nurse should not be judged on clinical skills alone but more in how they manage their thoughts and emotions bringing a holistic competency approach to care giving (Taskase and Teraoka, 2011) where emotional intelligence of the specialist nurse becomes crucial to personal and professional fulfilment (Codier, 2012, Bingle and Davidson, 2014) and efficacy of the role.

The interest in emotional intelligence and its relevance to nursing is ever increasing within the nursing literature (Kooker et al, 2007, Davies et al, 2010, Codier et al, 2011). Empirical studies include mental health nursing (Akerjordet and Severinsson, 2004, Hurley and Rankin, 2008, Hurley, 2012, Chaffey et al, 2012), nursing management (Downey et al, 2006), knowledge transfer (McConnell and Eva, 2012), recruitment (Rankin, 2013), community nursing (Davies

et al, 2010), nursing (McQueen, 2004, Por et al, 2011), cancer care (James et al, 2010, Codier et al, 2011) and death and dying (Banning and Gumley, 2010, Bailey et al, 2011). These studies all highlight the potential importance of emotional intelligence in nursing and its ability to articulate a form of intelligence that is an integral part of nursing.

Some authors link emotional intelligence to particular areas of clinical practice, suggesting the possession of knowledge, skills and competencies alone does not always reflect the entire ability of the nurse (Freshwater and Stickley, 2004). The nurse may possess the knowledge and skills but does not have the ability to transmit them and for a successful nurse-patient relationship a balance of both would seem essential. Indeed, as Fulton (2014) points out, the specialist nurse title does not itself indicate the performance of advanced practice. This potentially impacts on educational delivery as nurse educators need to focus on fostering broader nursing expertise other than mere competencies and skills, stressing the need for a pedagogical perspective of specialist practice.

Recommendations from the Institute of Medicine (IOM) report (2010) and the Benner et al study (2010) stated that nurses must possess specific competencies in order to interact therapeutically. These therapeutic interactions are multifaceted and deal with complex emotional and physical needs (Davies et al, 2010, Smith et al, 2009). Engaging in, developing and maintaining a therapeutic nursing relationship requires certain attributes and aptitude of the specialist practitioner. Manley and McCormack (1997) identified key attributes of specialist nursing practice as holistic knowledge, saliency, knowing the patient, moral agency and skilled know-how. Smith and Godfrey (2002) reported strong links between being a 'good' nurse and 'doing the right thing', suggesting not only elements of effective ethical practice

but also aptitude as a fundamental component to the therapeutic nursing relationship where self-awareness, self-management and good communication skills are paramount (Freshwater and Stickley 2004, McQueen, 2004, Codier, 2012, Bingle and Davidson, 2014). Other attributes are listed in Table 2.3.

Table 2.3 - List of attributes of the specialist nurse (Castledine, 2002, RCN, 2010a, Williams et al, 2010, Bingle and Davidson, 2014)

Attributes of the specialist nurse	
Emotional competence	Excellent interpersonal skills
Confidence	Sensitivity to patients' needs
Assertiveness	Approachability
Flexibility	Autonomy
Honesty	Willingness to self-review
Integrity	Motivation and enthusiasm
Patient advocacy	Innovation and change
Expect role modelling	A value for diversity

2.3.5 The specialist stoma care nurse

Stoma care nursing is not new; specialist nurses have worked in the field of stoma care for more than 40 years. The key skills and attributes required of the specialist stoma care nurse were outlined by Osbourne et al (2013) as part of a working party, for the World Congress of Enterostomaltherapy UK (WCET UK)(currently known as Association of Stoma Care Nurses UK (ASCN UK)) and listed in Table 2.4.

The specialist stoma care nurse is considered to be an advanced practitioner and according to the Career Framework (Skills for Health, 2004) should be working at level 6 or 7 (See Table 2.5). An individual practicing at this level of nursing is expected to be able to make clinical

Table 2.4 - Role of the specialist stoma care nurse (Osbourne, 2013)

The nurse should;
<ul style="list-style-type: none"> ○ Have an in-depth knowledge of the physical, psychological and emotional effects of stoma formation ○ Provide patient-centred care with a holistic approach ○ Plan patient care by focusing on the achievement of independence ○ Offer and deliver direct patient care ○ Teach new skills in the management of stoma care to patients and/or carers ○ Provide relevant information, at the appropriate time, for the patient ○ Co-ordinate patient care within the multidisciplinary team ○ Provide continuity of care from admission through to discharge with follow-up at home ○ Support the patient's family and supportive network

decisions based upon an advanced knowledge and a comprehensive understanding of the care and management associated with people living with a stoma and their family (Borwell, 1996, Wong and White, 2002, RCN 2013b).

This advanced level of knowledge incorporates both practical and theoretical knowledge (Benner, 1984), as together they contribute to the clinical decision making of the expert specialist nurse in stoma care. In terms of academic preparation, the completion of a nursing Degree and Masters level module in stoma care nursing was considered a benchmark on which to base specialist stoma care practice (Williams et al, 2010).

Benner (1984) implied some clinical situations are complex and models, theories and descriptions cannot always explain a practical solution to their complexities, adding that experience and mastery are necessary for a skill to be transformed to a higher level. Whereas a crucial component of nurses' knowledge and skills in delivering quality health care is basing practice on information emerging from the best available evidence (Sackett et al, 2000) emphasising clinical expertise or clinical reasoning is integrated through the best available

evidence. This infers the competence of the specialist stoma care nurse is defined by the ability of that nurse to demonstrate effectively a skill set of personal attributes and approaches, knowledge and skills required to fulfil the responsibilities of the role and forms the view of this study.

Table 2.5 – Career Framework for Health (Specialist Stoma Care nurse at Level 6 and 7) (adapted from Skills for Health, 2005)

Level	Competency
Level 6 (experienced/proficient)	Has expertise to use detailed theoretical and practical knowledge in stoma care nursing. Some knowledge is at the forefront of the speciality and involves critical understanding of theories and principles. The specialist stoma care nurse demonstrates mastery of methods and tools in complex care and demonstrates innovation in terms of methods used while having the ability to devise and sustain arguments to solve problems.
Level 7 (senior registered practitioner)	Regarded as a specialist or advanced practitioner in stoma care nursing. Is considered to have extended or expanded their role level 6. Working independently within a team, they deliver high levels of care to patients undergoing stoma surgery, act as a leader and change agent and are advocates for patients care.

The impact upon a patient's quality of life following stoma surgery has already been specified; this is not only due to the physical effects stoma surgery brings but also concerns psychosocial adjustment. Interventions and strategies are available to help a person maintain a good quality of life (Chelvanayagam and Emmanuel, 2011) and what suits one person may not suit another. The responsibility of the specialist stoma care nurse is to provide a patient-centred approach to the patient with a stoma. Patient-centred approach to care refers to a

multifaceted concept which addresses patients' needs for information, views the patient holistically, promotes understanding and develops a therapeutic nurse-patient relationship (Williams and Davis, 2005).

The underlying principles of a therapeutic relationship include respect, genuineness, empathy, active listening, trust and confidentiality (Cutcliffe and McKenna, 2005, Freshwater, 2007). The purpose is to support the patient, promote healing and support or enhance functioning (Chelvanayagam and Emmanuel, 2011). In understanding the perceptions of the person living with a stoma, the specialist nurse can appreciate what is important to that individual.

2.4 Education in advanced practice

Education is deemed essential to equip nurses to provide high quality care (Prime Minister's commission on the future of nursing: cited Sephton and Kemp (2013) whilst ensuring they are also fit for practice (NMC, 2015). However, educational requirements for specialist practice remain unclear. The most comprehensive document outlining the educational requirements is defined by the Welsh Assembly Government (2009, p23) where it is stipulated there is an expectation that 'all nurses in advanced practice will be graduates and in future will have completed post-graduate CPD appropriate to the demands of the post they fulfil'. Now that nursing in the UK has become an all graduate profession it can only be presumed that the rest of the UK will conform. As yet the NMC stipulate no further educational requirements beyond initial registration (McCorkell et al, 2015) whilst the RCN (2009b) recommends specialist roles to have at least Bachelors level honours degree. The need to ensure clinical practice is

evidence based is seemingly driven by the specialist nurses themselves, to attain Masters Degrees and Doctorates relevant to their expertise.

Following an extensive inquiry into failings at Mid-Staffordshire NHS Foundation Trust, Robert Francis QC, published his final report in February 2013. Amongst its 290 recommendations, the Francis Report (2013), as it is known, also expressed concern regards the education of healthcare professionals. The Report affirmed that patients must take priority. Resources must be assured so patients receive effective care from caring, compassionate and committed staff. The Report recommended that nurse education should be more focused on the practical requirements of compassionate care; compassion in practice being fundamental to all levels of nursing (Cummings, 2012).

Critical thinking allows advanced practitioners to explore and analyse evidence, cases and situations in clinical practice, enabling a high level of judgement and decision making.

Advanced practitioners are expected to demonstrate expertise in complex decision making in relation to their current role (DH, 2010). This includes determining what to include in the decision making process, and making a decision based on judgement and critical thinking/problem solving; in turn affecting the ability to practice autonomously. At level 6 or 7 of practice (Skills for Health, 2005) individuals require a comprehensive knowledge base as well as a high level of awareness of their own values and beliefs, however; disturbingly it has already been implied that some nurses retain job titles inferring specialist level of knowledge and competence but may possess neither of these.

2.5 Conclusion

This chapter has considered what is currently known about specialist nursing practice. The specialist nurse role profile is characterised by high levels of clinical skill, competence and autonomous practice but also needs to consider fostering a broader perspective of nursing expertise. The challenges of role clarity and consistency have been addressed. The lack of support by regulating professional bodies has been acknowledged suggesting this potentially leads to further discrepancies amongst specialist nurses themselves, other healthcare colleagues, commissioning bodies and stakeholders and employing healthcare organizations.

A key feature of this study was to explore how specialist stoma care nurses translate their knowledge and skills to facilitate the adaptation needs of patients with newly formed stomas. Stoma surgery is a life changing event; it was therefore necessary to consider the challenges faced by patients and to explore current colorectal surgery and stoma care nursing practices. This highlighted a change in the pace of information posing a challenge for the specialist nurse to be able to gauge the information needed by the patient to translate it in a manner the patient can comprehend. Likewise the failure to fully use instruments to aid the assessment of adaptation specifically for stoma patients was noted demonstrating the high level of applied knowledge, skill and ability required of the specialist nurse.

These conclusions from the literature related to the context of specialist nursing practice in the UK required further exploration. A critical appraisal of the research literature followed focusing on the patient experience and the transmission of specialist knowledge and skills with particular emphasis towards adaptation, as a means of further informing this study.

3. Literature review

3.1 Introduction

This chapter presents a review of the literature pertaining to the two connecting features of this study; the patient experience and the transmission of specialist knowledge and skills with particular emphasis towards adaptation. A critical appraisal of qualitative and quantitative studies is undertaken and leads to an overview of what is presently understood within current empirical studies, thus informing this study. The search strategy is therefore presented in such a way to illustrate the process and outcome of both features.

A thematic analysis of twenty-five empirical studies follows. Thematic analysis seeks to identify and bring together the main, recurrent and most important issues or themes arising from the body of literature and is most common method adopted with literature reviews (Mays et al, 2008). The approach was therefore to read the literature a number of times in order to seek out emerging themes. The research design, instruments used and findings of the reviewed literature are critically analysed. The synthesis of the key findings of this body of research culminates in the development of the conceptual framework (See Figure 3.1) which underpinned and guided the direction of this study.

3.2 Search strategy

3.2.1 Approach and process

Keywords for the search were identified based upon the contextual information provided in Chapter 2 (See Table 3.1a/b). The keywords were structured by using the specific acronym PIO (Kahn et al, 2003). From this key aspects of participant/population, issue/interest and

outcome were developed. This assisted with the organisation of formulating key words for two searches to take place; the patient experience (See Table 3.1a – Search 1) and knowledge transfer into specialist nursing practice (See Table 3.1b – Search 2).

Following steps 1 – 33 as highlighted in Table 3.1a/b, three electronic databases using the key words listed were searched with date limit set from 2001 to date and publications written in English. The date limit was stipulated to coincide with the UKCC's (2001) initial publication of the post-registration education and practice document (PREP). This was a set of standards and guidance designed to help provide a high standard of practice that since the establishment of the NMC has been revised several times in preparation for the re-validation process in 2016 (NMC, 2012). Advocating specialist education for specialist practice, this document was the beginnings of the formal recognition of higher levels of nursing practice, therefore empirical literature related to nursing, prior to this date was not relevant to this study.

Databases included Cumulative Index to Nursing & Allied Health Care Literature (CINAHL), Medline and PsycINFO. These databases were selected because CINAHL contains the largest citation of nursing literature, Medline is the oldest health-related index with extensive subject coverage and PsycINFO is a major literature resource in the field of psychology and psychiatry. In total 6,594 references were yielded from the search. This was considered too vast to explore and further strategies had to be considered in order to yield more manageable number of relevant references. It was therefore decided to seek more detailed

Table 3.1a - Keywords and facet analysis identified for search strategy - SEARCH 1 (Patient)

Participants (P)	Issue (I)	Outcomes (O)
Step 1. Patient	Step 4. Perception	Step 11. Adaptation
Step 2. Service User	Step 5. Experience	Step 12. Adjustment
Step 3. Combine 1-2 using 'OR'	Step 6. Information needs	Step 13. Quality of life
	Step 7. Communication	Step 14. Psychological care
	Step 8. Education	Step 15. Surgery
	Step 9. Understanding	Step 16. Combine 11-15 using 'OR'
	Step 10. Combine 4-9 using 'OR'	
Step 17. Combine 3, 10, 16 using 'AND'		
		Step 28. Colorectal cancer
		Step 29. Inflammatory Bowel Disease
		Step 30. Stoma
		Step 31. Combine 28-30 using 'OR'
Step 32. Combine 17 and 31 using 'AND'		

Table 3.1b - Keywords and facet analysis identified for search strategy - SEARCH 2 (Nurse)

Participants (P)	Issue (I)	Outcomes (O)
Step 18. Clinical Nurse Specialist	Step 19. Advanced Practice	Step. 11 Adaptation
	Step 20. Knowledge	Step 12. Adjustment
	Step 21. Transmission	Step 13. Quality of life
	Step 22. Information delivery	Step 14. Psychological care
	Step 23. Patient education	Step 15. Surgery
	Step 24. Communication	
	Step 25. Effectiveness	Step 16. Combine 11-15 using 'OR'
	Step 26. Combine 19 – 25 using 'OR'	
Step 27. Combine 18, 16 and 26 using 'AND'		
		Step. 28 Colorectal cancer
		Step. 29 Inflammatory Bowel Disease
		Step. 30 Stoma
		Step 31. Combine 28-30 using 'OR'
Step 33. Combine 27 and 31 using 'AND'		

literature relating to disease and stoma. This led to a further three steps within the search method (Steps 28- 33).

Following this a total of 1,330 references were yielded, of which 1,024 were discarded as the title and abstract was not relevant to the search (See Table 3.2). References were checked for duplicates, of which 225 were found.

Table 3.2 - Results from electronic searches

Database with dates	Search date	Number of hits retrieved from the search (at steps 32 + 33 of search strategy)	Number of articles discarded because of irrelevant titles	Number of duplicates from another database	Number of articles to be reviewed by title and abstract
CINAHL (1981-present)	August 2014	549	388	113	48
Medline (1946 – August week 2, 2014)	August 2014	453	347	83	23
PsycINFO (1806 – August week 3, 2014)	August 2014	328	289	29	10
Totals		1330	1024	225	81 (25 of which met the inclusion/exclusion criteria)

The titles, abstracts and keywords of the remaining 81 references were assessed using the inclusion and exclusion criteria presented in Table 3.3. As can be seen, ten specific inclusion and nine specific exclusion criteria were used. Literature was excluded if it referred only in general terms to patients' experiences, information provision or focused on quality of life and

psychological assessment tools. Eight references were not available in the English language and therefore were discounted. This left twenty-five references that met the inclusion criteria and in each case the full paper was retrieved.

Table 3.3 - Inclusion and exclusion criteria for the literature review

Inclusion criteria	Exclusion criteria
Specialist Nursing	General Nursing
Clinical Nurse Specialist	Nurse Practitioner
Advanced Practice	Midwifery
Studies exploring; patients experiences, perceptions, understanding, information need	
Studies exploring; Knowledge translation, information delivery, education, specialist and advanced nursing practice	Studies exploring; components of specialist role as well documented
Studies exploring; adaptation, adjustment, quality of life, psychological issues	Studies focusing on development or testing of a QoL/Psychological assessment tools
Research studies reported in English Language	
Published empirical studies	Non-empirical studies/reviews
Date limit 1994 – present	Unpublished doctoral thesis
Peer reviewed journals	Opinion papers

To further assess the quality of the empirical data in relation to patients' experiences, knowledge translation and specialist nursing practice; all references were appraised using an appraisal schedule from established guidelines (Mowatt et al, 2001). The scoring system within the schedule graded the studies as either 'weak', 'moderate' or 'strong' for both quantitative and qualitative studies. The appraisal schedule is presented in Table 3.4. The appraisal score for each paper is included in the summary of empirical studies; seventeen of the 25 references were graded as 'strong' (See Table 3.5).

Table 3.4 -The appraisal schedule (Mowatt et al, 2001)

Appraisal questions for quantitative research		Score
1.	Was the study prospective (3) or retrospective (1)?	3 or 1
2.	Were the outcome measures appropriate and clearly linked to the intervention?	0 1 2 3 4
3.	What method was used for the study? (4=RCT, 1=expert opinion)	0 1 2 3 4
4.	Were the methods adequately described and appropriate (within Cochrane guidelines)?	0 1 2 3 4
5.	How strong was the impact of the intervention on the identified outcomes?	0 1 2 3 4
6.	How accurate/precise was the measure of impact (p-values and CI)?	0 1 2 3 4
(0=lowest rating, 4=highest rating)		
Score summary		
	Weak	Moderate
	0-9	10-16
		Strong
		17-23
Appraisal questions for qualitative research		
1.	Was there a clear statement of the aims of the research?	0 1 2 3 4
2.	Was the sampling strategy clearly justified and linked to the target population?	0 1 2 3 4
3.	How accurate/precise was the measure of impact/relationship?	0 1 2 3 4
4.	Was the data analysis clearly linked to the themes/categories identified?	0 1 2 3 4
5.	Were the themes and categories linked to the aims of the research plausible?	0 1 2 3 4
6.	How transferable were the study's findings?	0 1 2 3 4
7.	What was the strength of the implications of the study for practice?	0 1 2 3 4
(0=lowest rating, 4=highest rating)		
Summary score		
	Weak	Moderate
	0-11	12-20
		Strong
		21-28

Table 3.5 - Summary of empirical studies

Researchers/ Country of study	Research design and Sample	Data collection/ Instruments used	Aim, Outcomes, Comments, Appraisal score (AS)
Allison et al (2013) UK	METHOD: Qualitative RD: Narrative SETTING: Acute Trust SAMPLING: Purposive PARTICIPANT (NUMBERS): 24 people with IBD (13 female) RR: N/A	Patient interviews	AIM: To explore the experiences of young people with inflammatory bowel disease (IBD) who face the prospect of or have undergone surgery for their condition. OUTCOME: Young adults need to be involved in the negotiations and decision-making. Concerns regards IBD same as adult; fear surgery and outcomes. Internet main information provider. COMMENTS: Story mapping used for analysis. Nurse Specialist (NS) role key. NS need to learn new ways of information delivery. AS: 23
Beaver et al (2010) UK	METHOD: Qualitative RD: Descriptive SETTING: Acute Trust SAMPLING: Purposive PARTICIPANT (NUMBERS): 28 RR: N/A	Patient interviews	AIM: To explore the patient perceptions of experiences of follow-up care after treatment for colorectal cancer OUTCOME: Continuity of care important. No stoma = little if no follow-up. Information 'trial and error'. Became obsessed with bowel habit. COMMENTS: NS role vital in providing information and support. Future strategies for providing follow-up care should be based on specialist skills and knowledge of nurse. AS: 19
Boot and Wilson (2014) UK	METHOD: Qualitative RD: Not indicated SETTING: Primary care SAMPLING: Purposive PARTICIPANT (NUMBERS): NS (n=12) RR: N/A	Nurse interviews	AIM: To identify challenges experienced by NS when facilitating advanced care planning conversations to inform education OUTCOME: 3 key factors; assessment, patient's physical condition, nurse-patient relationship. NS = active listening, picking up cues and developing opportunity for timely discussions COMMENTS: Advanced care planning conversations have unforeseen consequences/risks AS: 21

Researchers/ Country of study	Research design and Sample	Data collection/ Instruments used	Aim, Outcomes, Comments, Appraisal score (AS)
Chapple et al (2006) UK	METHOD: Qualitative RD: Grounded theory SETTING: Hospice care SAMPLING: Purposive PARTICIPANT (NUMBERS): Terminally ill patients (n=41) RR: N/A	Patient interviews	AIM: To explore the patient experience of terminal illness OUTCOME: Patients valued the work of NS regards; practical help, talking and listening, clinical information, advice, symptom control, help with communication, flexibility, availability. Participants reported various levels of emotional support as not always timely. Participants reported distress at early referral due to public view of hospice care COMMENTS: Malignant and benign terminally ill patients included. AS: 19
Danielsen et al (2013b) Denmark	METHOD: Qualitative RD: Phenomenology SETTING: Acute Trust SAMPLING: Purposive PARTICIPANT (NUMBERS): 15 RR: N/A	Patient focus group	AIM: To explore the impact of a permanent stoma on patients everyday lives to gain further insight into their need for ostomy-related education. OUTCOME: Timing of pre-op teaching and participant's ability to receive new information seen as critical. Stoma creation led to feelings of stigma, worries about disclosure. Self-imposed strategies included social isolation. Preferences towards group teaching. COMMENTS: Levels of information should be tailored to patient need. AS: 21
Dowling (2008) Ireland	METHOD: Qualitative RD: Phenomenology SETTING: Oncology SAMPLING: Purposive PARTICIPANT (NUMBERS): Oncology nurses (n=23) Oncology patients (n=30) RR: N/A	Nurse interviews	AIM: To explore the meaning of nurse-patient relationship OUTCOME: 3 themes of intimacy; developing, experiencing and outcome. COMMENTS: Peer support essential, emotional self-awareness required AS: 19

Researchers/ Country of study	Study design and sample	Data collection/ Instruments used	Aim, Outcomes, Comments, Appraisal score (AS)
Dowding et al (2009) UK	METHOD: Qualitative RD: Ethnography SETTING: Primary Care SAMPLING: Purposive PARTICIPANT (NUMBERS): Heart Failure NS, Observation (n=6), Interviews (n=12) RR: N/A	Observation of nurses Nurse interviews	AIM: To explore the decision process of nurse specialists OUTCOME: 2 key role components identified; pharmacological management, palliative care. Recommend a decision-making tool to assist process COMMENTS: Decisions regards medication much easier to undertake in comparison to when to make palliative care referral AS: 21
Gerrish et al (2011) UK	METHOD: Qualitative RD: Case studies SETTING: Hospital and primary Care Trust SAMPLING: Purposive PARTICIPANT (NUMBERS): Advanced Practice nurse Interviewed (n=23) of which (n=5) observed RR: N/A	Observation of nurses Nurse Interview	AIM: To identify approaches to promoting evidence-based practice in advanced practice OUTCOME: Role of brokering in advanced practice is complex and multi-faceted; includes active processes of problem-solving and facilitating change. Brokering knowledge development includes; role modelling, teaching, clinical problem-solving, change agent COMMENTS: APN uniquely placed to encourage knowledge brokering activities. Change agent seen as component of CNS. AS: 19
Grogan and Timmins (2010) Ireland	METHOD: Quantitative RD: Descriptive survey SETTING: Out-patient clinic SAMPLING: Convenience PARTICIPANT (NUMBERS): Hep C +ve patient (n=106) RR: 53% (106/201)	Non-validated Questionnaire	AIM: To identify patients perceptions of support from NS OUTCOME: Overall satisfied with support received; particularly info re contraception. Significant correlation between support received and reported genotype noted. Need to recognise psychological needs of differing modes of HCV infection COMMENTS: Some information deficits reported particularly related to information giving and psychological care. Educational strategies need further exploration. AS: 17

Researchers/ Country of study	Study design and sample	Data collection/ Instruments used	Aim, Outcomes, Comments, Appraisal score (AS)
Haugen et al (2006) USA	METHOD: Quantitative RD: Descriptive survey SETTING: Out-patient department SAMPLING: PARTICIPANT (NUMBERS): Stoma for 6 months or longer (147) RR: 74% (147/200)	Non-validated questionnaire and validated – Perioperative factors of Ostomy Adjustment The Ostomy Adjustment Scale (OAS)	AIM: To identify pre-operative factors associated with long-term adjustment to a stoma. OUTCOME: Report overall good adjustment to stoma. Positive factors included independence, stoma visible and no complications. Adjustment better if provided with pre-operative information. COMMENTS: More distress caused by obtaining supplies – not relevant to UK AS: 19
Howell et al (2014) UK	METHOD: Qualitative RD: Ethnography SETTING: Primary care SAMPLING: Purposive PARTICIPANT (NUMBERS): 4 NS observed interviews with 34 palliative care patients RR: N/A	Nurse observation and field notes	AIM: To describe community palliative care – CNS's activities during interactions with patients OUTCOME: Wide range of knowledge needed. Acts as liaison, responding to fluctuating needs of patients. Research has helped NS's describe their role to commissioners/stakeholders COMMENTS: Data saturation not complete. NS's described as senior nurses working as part of team. Three had extended qualifications. AS: 16
Husson et al (2013) The Netherlands	METHOD: Quantitative RD: Descriptive Survey SETTING: Primary care SAMPLING: Purposive PARTICIPANT (NUMBERS): Cancer survivors from Cancer Registry RR: 69% (3080/4446)	Validated questionnaire – EORTC-QLQ- INFO25 Brief Illness perception	AIM: To provide insight into the relationship between information provision and illness perceptions among cancer survivors OUTCOME: Participants illness perception improved with tailored information = coherent understanding ?leading to better health- related quality of life COMMENTS: Cancer survivors included those with lymphoma, myeloma (32%), endometrial (24%) and colorectal cancer (44%). AS: 17

Researchers/ Country of study	Study design and sample	Data collection/ Instruments used	Aim, Outcomes, Comments, Appraisal score (AS)
Kvåle (2007) Norway	METHOD: Qualitative RD: Phenomenology SETTING: In-patient SAMPLING: Purposive PARTICIPANT (NUMBERS): 20 RR: N/A	Patient interviews	AIM: To explore if cancer patients wanted to discuss their feelings and difficult emotions and why. OUTCOME: Themes; cognitive avoidance and distancing, normalisation, finding meaning and living in the present, support from family and friends COMMENTS: Knowing when to intervene and accepting patient does not want to talk AS: 21
Leary et al (2014) UK	METHOD: Quantitative RD: Online Survey SETTING: Lung Cancer Service, UK SAMPLING: Self-selected PARTICIPANT (NUMBERS): Lung Cancer nurse specialist (LCNS) (n=78) RR: 78% (78/100)	Non-validated questionnaire	AIM: To examine the complexity of the national lung cancer service OUTCOME: Focused on workload of LCNS in relation to best practice guidelines. Measured unmet needs of patient care. Lack of time and organisational issues attributed to unmet needs COMMENTS: Mean caseload per NS = 101-200 patients, work left undone; proactive management(n=52), holistic needs assessment (n=46), psychological needs (n=26), financial issues (n=17), meeting information needs (n=16), symptom management (n=13) AS: 21
Lester et al (2014) USA	METHOD: Quantitative RD: Survey SETTING: Online SAMPLING: Purposive PARTICIPANT (NUMBERS): RN's, NS's and NP's working in cancer care RR: 31% (n=223)	Non-validated questionnaire	AIM: To examine oncology nurse knowledge about cancer survivorship OUTCOME: Vast gaps in knowledge reported; lack of ability to inform patients about chemotherapy; impact of cancer on family, relationships, sexuality, employment; genetic risk; fertility, finance, insurance. 70% reported not 'happy' to explain pathology reports to patients. Most knowledge imparted related to healthy lifestyle habits. COMMENTS: Cancer nursing experience; 30% >30yrs, 27% >15yrs, years in nursing 51% >15yrs, 66% post-grads AS: 18

Researchers/ Country of study	Study design and sample	Data collection/ Instruments used	Aim, Outcomes, Comments, Appraisal score (AS)
Lithner et al (2012) Sweden	METHOD: Quantitative RD: Survey SETTING: Acute Trust SAMPLING: Purposive PARTICIPANT (NUMBERS): Those who have undergone colorectal surgery with no stoma (n=100) RR: Not reported	Validated questionnaire – EORTC QLQ-C30 INFO25 CR38	AIM: To explore how patients perceive information after surgery for colorectal cancer, what their information needs are and to determine factor affecting received information OUTCOME: Most information was disease and test related. Timely/relevant information appreciated. More information needed; physical/emotional problems, diet, medication, skin care. COMMENTS: ‘Waiting for information creates uncertainty’. Patients reporting poorer pre-op prep received less information. AS: 20
McCaughan et al (2011) UK	METHOD: Qualitative RD: Descriptive SETTING: Out-patient SAMPLING: Convenience PARTICIPANT (NUMBERS): Colorectal cancer at initial diagnosis (n=24, 14 female) RR: N/A	Interviews	AIM: To explore how people with colorectal cancer compare experiences, what this meant to them and its context. OUTCOME: Emerging themes; comparison; object of comparison; types of information gathered, effects of comparison COMMENTS: Patients supplement information from family, friends, other cancer patients, support groups, media. Clinic like ‘market place’ for exchange of information. Challenges for nurses; to harness, complement and clear misconceptions. AS: 21
O’Connor et al (2010) UK	METHOD: Quantitative RD: Survey SETTING: SAMPLING: Purposive PARTICIPANT (NUMBERS): Ca. Rectum (n=40, 24 male) RR: Not reported	Validated questionnaire – Toronto Information needs (TINQ)	AIM: To explore the information needs of patients with cancer of the rectum and how patients felt that their information needs were met. OUTCOME: Higher satisfaction with information received by male participants. NS’s found to be invaluable source of information. Tailored information very important. COMMENTS: NS should explore patient’s information needs and design appropriate resources. AS: 17

Researchers/ Country of study	Study design and sample	Data collection/ Instruments used	Aim, Outcomes, Comments, Appraisal score (AS)
Ream et al (2009) UK	METHOD: Mixed methods RD: Exploratory-descriptive SETTING: Specialist Practice SAMPLING: NS – Purposive Male service users - Snowball PARTICIPANT (NUMBERS): NS 23, Male service users (n=40) RR: Not reported	Validated Diary/contact sheets Patient interviews	AIM: To explore role of Prostate NS, explore contribution to care and influence on the patient's experience. OUTCOME: Variation in qualification and experience amongst PCN's Support and information varied. Patients valued role of PCN but reported unmet psychological and sexuality-related care needs. COMMENTS: Caseloads varied greatly. Patient care difficult to measure. AS: 18
Smith et al (2002) UK	METHOD: Quantitative RD: RCT SETTING: Out-patients SAMPLING: Convenience PARTICIPANT (NUMBERS): Controlled group 1, non IBD (n=50), controlled group 2, IBD (n=50 CD, 50 UC) RR: Not indicated	Validated tools /questionnaires - Disease Activity Score SF-36 HAD Non-validated nurse-led counselling package	AIM: To examine the effects of psychosocial counselling in inflammatory bowel disease (IBD) OUTCOME: Disease activity score/medical therapy same in both groups. Low mental health, ↓ social activity scores, significantly ↑ anxiety/adaption difficulties reported in group 2. Health-related QoL improved in controlled group 2 at 6 mths irrespective of disease but not sustained for 12. COMMENTS: Counselling package = information provision (info booklets/patient support) and psychological intervention (adapted stress management programme) AS: 19
Tarrant et al (2008) UK	METHOD: Mixed methods RD: Survey-Exploratory SETTING: Out-patient SAMPLING: Convenience/Snowball PARTICIPANT (NUMBERS): People with prostate cancer (n= 289) RR: 60% (289/481)	Validated Questionnaire Interviews	AIM: Findings from 2 studies; To explore the experiences of information delivery, involvement in decision-making in specialist and non-specialist care and patients' views on the role and value of the NS OUTCOME: More positive experience when specialist nurse involved. Unique role reported but felt some psychological needs were not met COMMENTS: Interviews offered more specific aspects of role; time to talk, reflect on diagnosis, advice, support and information. AS: 18

Researchers/ Country of study	Study design and sample	Data collection/ Instruments used	Aim, Outcomes, Comments, Appraisal score (AS)
Thompson et al (2008) UK	METHOD: Quantitative RD: Judgement analysis survey SETTING: Acute care SAMPLING: Purposive PARTICIPANT (NUMBERS): NS (n=29) RR: Not reported	Non-validated judgement tasks	AIM: To explore decision-making process of NS in heart failure OUTCOME: Judgements varied greatly. Judgements regards drug titration was easier than palliative care referral. Education or clinical experience were not related to information processing COMMENTS: Title 'Nurse Specialist' should not equate to clinical expertise AS: 18
Thorpe et al (2014) UK	METHOD: Qualitative RD: Phenomenology SETTING: Acute Trust SAMPLING: Purposive PARTICIPANT (NUMBERS): Stoma patients (n=12), NS (n=10) RR: N/A	Nurse and patient interviews	AIM: To explore the individual experience of living with a new stoma and interactions with healthcare over time with the purpose of informing health care services OUTCOME: Emerging themes: relationship with NS; being prepared; gaining autonomy. COMMENTS: Focus is towards redefining plan of care to assist with adaptation/adjustment. Highlighted powerful influence NS has in facilitating this process. AS: 23
Worster and Holmes (2008) UK	METHOD: Qualitative RD: Phenomenology SETTING: Out-patient SAMPLING: Purposive PARTICIPANT (NUMBERS): 20 (10M/10F) RR: N/A	Patient interviews	AIM: To explore patients experience following surgical removal of colorectal cancer with end-to-end anastomosis and before adjuvant therapy. OUTCOME: Emerging themes; I couldn't believe it; being alone; informational needs; protecting family; unexpected consequences of investigations; loss of control COMMENTS: Both physical and psychological difficulties expressed AS: 20

Researchers/ Country of study	Study design and sample	Data collection/ Instruments used	Aim, Outcomes, Comments, Appraisal score (AS)
Wylie et al (2013) Hong Kong	METHOD: Quantitative RD: Survey SETTING: Out-patient SAMPLING: Purposive PARTICIPANT (NUMBERS): Breast and colorectal cancer (n=201, Breast 97, CRC 104) RR: 89% (n201/227)	Validated questionnaires – Supportive care needs (SCNS-SF34) Hospital Anxiety and Depression Scale (HADS) Memorial Symptom Assessment (MSAS- SF) Chinese Patient Satisfaction	AIM: To understand the supportive care needs of breast and colorectal cancer patients, identifying prevalence and correlate unmet needs OUTCOME: Standardized Likert-summed scores calculated relating to supportive care needs, psychological distress, symptom distress and patient satisfaction. Breast cancer patients expressed slightly greater unmet needs. Hospital staff needed to show more compassion, information needed regards sexuality and specific person to co-ordinate care desired. COMMENTS: Different healthcare system but demonstrates need for specialist knowledge AS: 19

3.3 Overall findings

A thematic analysis framework (Braun and Clarke, 2006) was applied. The empirical studies selected for this literature review were read and re-read as a means of familiarisation, during which time themes were searched for. Several themes recurred, in relation to the study emerged: patient perceptions and experiences, unmet patient needs, giving and getting information, timely conversations and efficacy of the specialist nurses' knowledge, skill and aptitude (See Table 3.6). No studies exploring the explicit nature of knowledge transmission or information exchange amongst specialist practice were identified.

The majority of references focused on cancer with only two exploring inflammatory bowel disease and one relating to Hepatitis C virus; ten references were stoma-related. Studies reviewed originated from a variety of countries demonstrating the international nature of the issues explored; USA (Haugen et al, 2006, Lester et al, 2014), Denmark (Danielsen et al, 2013b), The Netherlands (Husson et al, 2013), Scandinavia (Kvåle, 2007, Lithner et al, 2012), Hong Kong (Wylie et al, 2013).

Thirteen qualitative and 10 quantitative research methodologies were represented with 2 studies using a mixed method approach (Tarrant et al, 2008, Ream et al, 2009). Each of the references were appraised using the appraisal schedule as highlighted (See Table 3.4) and where appraised as medium to strong, offering both objective and subjective perspectives to the review. Patient experiences in relation to information delivery and transfer of specialist knowledge were considered (Haugen et al, 2006, Grogan and Timmins, 2010, McCaughan et al, 2011, Allison et al,

2013, Danielsen et al, 2013b, Thorpe et al, 2014). As a result, unmet patient needs were reported (Tarrant et al, 2008, Ream et al, 2009, Beaver et al, 2010, Leary et al, 2014). Emphasis was placed upon the features of advanced communication and the challenges to specialist nurse-patient situations (Smith et al, 2002, Chapple et al, 2006, Kvåle, 2007, Ream et al, 2009, Howell et al, 2014, Leary et al, 2014). Key roles, responsibilities, knowledge and skills of specialist nursing practice were also considered (Smith et al, 2002, Ream et al, 2009, Howell et al, 2014, Lester et al, 2014).

Table 3.6 - Themes and key empirical sources

Theme	Key empirical sources
Patient experiences/perceptions	Allison et al (2013), Beaver et al (2010), Danielsen et al (2013b), Grogan and Timmins (2010), Haugen et al (2006), Thorpe et al (2014)
Unmet patient needs	Beaver et al (2010), Danielsen et al (2013b), Leary et al (2014), Ream et al (2009), Wylie et al (2013)
Giving and getting information	Allison et al (2013), Beaver et al (2010), Danielsen et al (2013b), Haugen et al (2006), Husson et al (2013), Lithner et al (2012), McCaughan et al (2011), O'Connor et al (2010), Thorpe et al (2014), Worster and Holmes (2008), Wylie et al (2013)
Timely conversations	Chapple et al (2006), Danielsen et al (2013b), Haugen et al (2006), Kvåle (2007), Tarrant et al (2008), Thorpe et al (2014)
Efficacy of Nurse Specialist	Boot and Wilson (2014), Dowling (2008), Dowding et al (2009), Gerrish et al (2011), Howell et al (2014), Leary et al (2014), Lester et al (2014), Ream et al (2009), Smith et al (2002), Thompson et al (2008)

3.4 Emerging themes

3.4.1 Patient experiences and perceptions

This thesis has already presented the wealth of literature acknowledging the variety of physical and psychological issues faced by patients with newly created stomas (See Chapter 2). References within this review mirrored these findings but were selected for their focus of information needs from the patient's perspective (Haugen et al, 2006, Allison et al, 2013, Danielsen et al, 2013b, Thorpe et al, 2014).

Allison et al (2013) explored the experiences of young people with inflammatory bowel disease who faced the prospect of, or had undergone surgery for the condition. Within their qualitative study, 24 participants between the ages of 18-25 were interviewed; 11 were male and 17 had Crohn's disease. Little is known of the experiences of this group of patients. This study mirrors other previous empirical work, affirming anxieties and concerns for this group of patients are comparable with others, regardless of age (Kelly, 1992, White and Hunt, 2002, Notter and Burnard, 2006, Haugen, 2006, Danielsen et al, 2013b). Adjustment was described as a gradual process where concerns relating to the stoma decreased as they regained their health. The key factor in adjustment was described by participants as the ability to see the positive changes that the stoma brought to their lives. Strategies to achieve this included making positive comparisons, having the right attitude or just 'getting on with it'; supported by advice and information received from health care professionals.

Stoma care related educational needs of patients were explored by Danielsen et al (2013b) in their recent qualitative study. The purposive sample comprised of 15 participants who were divided into two focus groups; group 1 – colorectal cancer + stoma (n=9), group 2 – non colorectal cancer + stoma (n=6). Each focus group explored lived experiences associated with creation of a stoma and its influence on daily living. Two key themes emerged; being different and training in living life with a stoma. One aspect of 'being different' was disclosure and communicating openly about their stoma; in most cases this led to avoiding social situations. Reportedly participants had little hesitancy discussing their underlying condition compared to speaking about the stoma. As one participant pointed out,

"..... they do not know what a stoma is, I didn't either until I had one, so if I start telling everyone then you have to explain it all" (Danielsen et al, 2013b, p409).

Feelings of this nature gave rise to the importance of supporting the patient by providing appropriate information and developing their strategies for coping, as Smith et al (2007) suggest, feelings of disgust towards the stoma could be negatively associated to adaptation to living with a stoma.

A quantitative survey by Haugen et al (2006) considered the pre-operative factors associated with long term adjustment to stoma formation. The authors conducted the survey using two validated tools; Perioperative Factors of Ostomy Adjustment (PFOA) and Ostomy Adjustment Scale (OAS) as well as a demographic form. Posting to 200 potential respondents with a stoma, a response rate of 74% was achieved.

The majority of respondents were older people who were married (74%, 109/146) and Caucasian (99%, 145/146). Their mean age was 65 years, most had completed high school education, half were retired and a quarter was in full time employment. Fifty-six percent had an ileostomy, 28% a colostomy and 15% a urostomy; average length of time with a stoma 10 years. Seventy-nine percent claimed the creation of their stoma had cured the disease or disorder that had led to its creation; inflammatory bowel disease (49%), colorectal cancer (45%), diverticular disease (3%), other (1%). This suggested a positive outlook towards living with a stoma. The authors reported a good overall adjustment score following formation of a stoma, citing information giving and ongoing care as the main reasons.

Further patients perceptions were explored in Grogan and Timmins's study (2010) as they explored knowledge transmission by specialist nurses. Patients' perceptions of information and psychological support received from nurse specialist during Hepatitis C virus (HCV) treatment were investigated. Using a quantitative descriptive design, a non-validated 59-item questionnaire was handed to 201 patients listed as having received HCV treatment and specialist nurse intervention at a recognised Liver Unit in Ireland, as they attended the HCV outpatient clinic. The response rate was 53% (n=106).

Overall respondents were very satisfied with the support and information they received. There were no statistically significant differences between overall

satisfaction and gender, age, genotype and risk factor. However, there were significant correlations between support given and reported genotype, suggesting more support was needed with genotype 1, where most are infected by blood or blood products. Patients perceptions of psychological support received were high although low scores were reported in those requiring long-term support. This paper indicates the need for information giving in the long term stressing the importance of follow-up care.

Ongoing care was also a key factor highlighted in the study by Beaver et al (2010). In this qualitative study, the authors explored patients' perceptions of their experiences in follow-up care, following treatment for colorectal cancer. The purposive sample included 28 participants attending surgical out-patients; half had a stoma. Interviews took place at six to 12 month intervals over five years. A thematic analysis identified one dominant theme, 'knowing what to expect' and several sub-themes, living with altered bowel function, trial and error, information and support from nurse specialist. The study lent support to the argument that patients' psychosocial and information needs are not met by traditional hospital follow-up appointments. In-patient information and support was in abundance, particularly for those with a stoma. However, following discharge patients without a stoma reported facing many uncertainties, citing they felt 'more vulnerable' as there was no follow-up whilst at home.

Thorpe et al (2014) explored individual experience of living with a new stoma and interactions with health care overtime so to inform the provision of health care. Using a phenomenological approach, 12 patients and 10 healthcare professionals were interviewed and three key themes emerged; the relationship with healthcare professional, being prepared and regaining autonomy. The authors reported that discharge from hospital was seen as a positive step towards greater autonomy. However, current patient recovery programmes was also seen to cause patients to feel rushed in becoming independent in their stoma care, resulting in them feeling ill-prepared on discharge. This resulted in on-going dependence upon specialist services for emotional and practical support, indicating unmet patient needs.

3.4.2 Unmet patient needs

Unmet needs varied. Specialist nurses' perspective was a feeling of not being able to fulfil their role, whilst patients expressed delayed ability to adjust emotional as they had not received adequate psychological support.

Leary et al (2014) reported the majority of specialist nurses felt they left work undone against best practice guidelines, due to workload and lack of organisational support. Reporting as a part of a larger study, the authors examined the scale and complexity of the national lung cancer service in the UK. Exploring caseloads, patient pathways and specialist nursing interventions, the authors revealed that varying size of patient caseloads lead to the dissatisfaction amongst specialist nurses at not

completing care to best practice guidelines. The authors clearly demonstrated that size of caseload impacted upon provision of specialist care, and illustrate this with an example of a respondent's narrative by stating,

"I think the size of our caseload prevents us being as proactive as we would like to be – we feel we are a reactive service. It is impossible for us to maintain regular contact with patients and so we are very active at certain points of the pathway, especially around diagnosis and end of life" (NS, Leary et al, 2014, p25).

Large caseloads leading to increased work-load was clearly an issue as specialist nurses are often reported to be regularly working unpaid overtime (Leary et al, 2008, Griffiths et al, 2013). These findings reported sizeable patient caseloads and time constraints inferring the priority for care is physical rather than a balance of physical and psychological care; care left undone not only goes against national best practice guidelines (NICE, 2006) but also represents a source of dissatisfaction amongst specialist practice (Leary et al, 2014). Frustrations were reported by specialist nurses as they tried to balance role expectations with the realities of clinical workload (Husband and Kennedy, 2006, Fulton, 2014). This was also mirrored in other studies where real-time activities of specialist practice were explored; time taken to carry out activities outweighed contracted hours (Ream et al, 2009, Oddsdóttir and Sveinsdóttir, 2011, Norton et al, 2012), resulting in a review of service provision.

Ream et al (2009) explored both patients and specialist nurses perspective of care needs. The mixed methodology used offered the opportunity for comparisons between the patient and nurses perspective to be discussed. Caseloads were

reported as comprising men diagnosed with prostate cancer at different stages of disease and treatment trajectories, requiring the nurse specialist to undertake various working patterns, to reflect the demands of the patient. Variations in service provision were noted as a result of different experiences in knowledge, size of caseload and organisational constraints. Within the findings, the authors illustrated the value placed on the specialist nurse by the participants, recognising their stages of importance to be, at diagnosis and treatment decision-making. The nurse participants, too, reportedly recognised their contribution to these stages of the patient's trajectory, stressing the importance of psychological care in facilitating the adjustment required of the patient to come to terms with their diagnosis and prognosis. However, the participants highlighted unmet psychological needs which worsened over time. Arguably nurse specialists are ideally placed to facilitate the patients' needs as they adapt but would need to reassess the way they transfer information and provide care ensuring it is appropriate for the patient to comprehend.

Danielsen et al (2013b) reported social and emotional needs as a challenge; patients focused on the information provided by health care professionals and reported variable levels of interest in stoma care by nursing staff. In their study, one participant reportedly believed the stoma would offer a 'non-problematic life' from the information disclosed to him by healthcare professionals prior to surgery. When the stoma did become problematic, feelings of isolation, stigma and abnormality ensued.

Wylie et al (2013) examined the prevalence of supportive care needs in breast and colorectal cancer patients to identify prevalence to correlate unmet needs. Of the 201/227 (89%) patients recruited, 97 were female patients with breast cancer aged between 27-74 years and 104 patients with colo-rectal cancer (male n58) between ages of 45-84 years. Using a cumulative standardized Likert Scale, four validated instruments measured supportive care needs (Supportive Care Needs Survey SCNS-SF34), psychological distress (Hospital Anxiety and Depression Scale (HADS), patient satisfaction with care (Chinese Patient Satisfaction Questionnaire) and symptom distress (Memorial Symptom Assessment Scale (MSAS-SF). Breast cancer patients were reported to experience more unmet needs than colorectal cancer patients ($P=0.017$) however what was reported by both groups was the need for hospital staff to address issues relating to sexuality and relationships, to show sensitivity and compassion and to have one member of hospital staff allocated to their care that they could talk to about all aspects of their condition, treatment and follow-up care. The specialist care for both breast and colorectal care was acknowledged as reducing some uncertainty but information was constantly required to alleviate participants' worries and concerns along their cancer pathway.

Within Beaver et al's (2010) study, patient narratives clearly illustrate uncertainty and doubt as their concerns were not addressed with regards to their condition and what to expect. Participants often reported not understanding whether their physical symptoms were 'normal' for patients undergoing colorectal surgery.

Patients clearly need information in a way they understand (Danielsen et al, 2013b) which is central to information giving.

3.4.3 Giving and getting information

Whilst the importance of information giving is acknowledged (DH, 2000, NICE, 2004) research continues to show considerable variation in the information needs of patients (Worster and Holmes, 2008, Ng et al, 2012). Although patients want as much information as possible it is important to know what type of information they want and need (Mayer et al, 2007), and for it to be transmitted in a manner they understand (Worster and Holmes, 2008, Allison et al, 2013, Danielsen et al, 2013b).

Studies within the review demonstrated that most patients prefer a direct, honest and comprehensive approach to information giving (Danielsen et al, 2013b, Thorpe et al, 2014) implying specialist knowledge, skills and expertise are a key factor in the patient's adaptation. However, both Worster and Holmes (2008) and McCaughan et al (2011) reported on the significant variation of information needed. McCaughan et al (2011) refer to levels of unwanted information. In-depth interviews were carried out to a convenience sample of patients with colorectal cancer. Types of information needed related to prognosis, treatment and how others had coped. However, patients found themselves besieged by worrying tales and experiences that might cause greater concern. Referred to this as a 'market place' for the exchange of information, McCaughan et al (2011) reported most information was gathered from

clinics, wards and hospital corridors. The specialist nurse is, therefore challenged to harness the information gathered, clear any misunderstandings and reinforce relevant information provision.

Exploring the pre-operative experiences of patients with colorectal cancer, Worster and Holmes (2008), revealed significant variation in the amount and detail of information wanted indicating a need to be sensitive to individual requirements. The success of information giving is not only influenced by the amount required but also how the individual understands and interprets the information given. A patient's narrative from the study illustrated this, indicating information was,

"..... wonderful, there was stacks of it, she loaded me up with so much information, it was unbelievable" (Worster and Holmes, 2008 p420),

to

"I was given leaflet after leaflet right up until coming into hospital. I didn't read it at first and when I did it frightened me" (Worster and Holmes, 2008 p420).

Possessing the skills to transmit information, clearly and concisely, was an attribute required of the specialist nurse (Freshwater and Stickley, 2004, Kooker et al, 2007).

Lithner et al (2012) illustrate that there was room for improvement where information sharing is concerned. In their quantitative survey, instruments were adapted to measure diagnoses and treatment (QLQ-C30), information received by the patient (INFO25) and issues relating to living with colorectal cancer (CR38). Of the 100/161 participants in the study 45% were female and mean age was 70 years.

The study demonstrated that almost 50% of patients did not recall or were not given specific information regarding the pre-operative process of their colorectal surgery. Patients could not recall whether specific information was given about the possible result of surgery, how to handle symptoms when at home and prognostic information about their future. Specialist nurses need to be mindful of this and assist the patient in developing responsive strategies, so that when the time is right for them they can engage in conversations that will help them understand.

Allison et al (2013) reported that young adults with inflammatory bowel disease respond negatively to those who 'knew best' and did not provide opportunities for discussion and negotiation. This has direct implications for those offering information highlighting the importance to engage with patients of all ages and backgrounds in a manner appropriate to them in order to discuss perceptions of disease management and surgery, decision making process, concerns, support and ways of coping as and when the patient wants to.

O'Connor et al (2010) reported younger patients needing higher levels of information about financial and employment issues, whereas older patients focused on prognosis. Using a validated questionnaire (Toronto Information Needs Questionnaire (TINQ), the study surveyed a sample of 40 patients with a diagnosis of rectal cancer at 18 months post-surgery. The average age of the participants was 66 years (44-86years) and 60% were male (n=24), 87.5% (n=35) had undergone stoma surgery and 15% (n=6) had undergone closure of the stoma within 18 months of

surgery. Statistical variances were reported with regards to information needs in relation to gender. Male participants felt it was more important to know where their family could go to get help dealing with their illness ($P=0.346$), if they could wear normal clothing ($P=0.184$), how the treatment works against cancer ($P=0.158$), if they were going to need to get help taking care of themselves ($P=0.147$) and how to prepare for investigations ($P=0.074$). Participants indicated that information needs, with ratings of high levels of important, were not adequately addressed, these included understanding results following investigations, understanding treatment plans and psychosocial needs. The specialist stoma care nurse was quoted to be the patients' main source of information. Consequently, the authors recommended early referral to the specialist stoma care nurse to ensure the patient as adequate preparation time and the information they need. The Patient Information Forum (2013) recognises that if help and support is tailored to the patients need it increases their knowledge and understanding, offering them a sense of empowerment as they take on the ability to cope with the effects of their illness.

Haugen et al (2006) confirmed this by specifying how the specialist nurse was seen as an expert in the trajectory of the illness, who spends a considerable amount of time with the patient, explaining, re-explaining and translating information in terms the patient could understand. Beaver et al (2010) stressed the importance of information delivery needing to be clear in such a way the patient understood. In their qualitative study, patients often felt overloaded with information highlighting that they may well have been informed but did not understand because they were

overwhelmed by the amount of information provided. This emphasises the patients' need for the right information, at the right time, in an appropriate manner for them to comprehend (Danielsen et al, 2013b).

In Husson et al's (2013) study, two validated questionnaires were used to measure cancer survivorship (QLQ-INFO25) and patient background characteristics (ECR) in order to uncover the relationship between information provision and illness perception among cancer survivors. Of the 3080/4446 respondents (69%) various cancer diagnoses were reported; colorectal (n1352), endometrial (n742), non-Hodgkin lymphoma (n716), Hodgkin lymphoma (n150), multiple myeloma (n120). Those with lymphoma were noted to be significantly younger than others groups whose average age was stated to be 66 years (41-70 years). Much of the information provided was described as disease and treatment focused, even though past research has identified a broader information need including psychosocial well-being (Miller and Sullivan, 1999). Patients differed in the type and amount of information needed: variants included gender, age, cultural background, cancer type, educational level and coping style. Overall, patients expressed the need for timely, tailored information, supported by a discussion with the specialist nurse, however, tailored information will change, as too will timely.

3.4.4 Timely conversations

Time is essential to adapting to life with a new stoma as it brings improved physical, social and psychological functioning (Smith et al, 2007, Allison et al, 2013), therefore the nature of care is fundamental and influences patient's recovery. Thorpe et al (2014, p384) reported an element of rushing patients in order to meet 'target-driven accelerated patient discharge', with the potential negative effect on a patient's ability to achieve self-care. Haugen et al (2006) supported the need for pre-operative education by the nurse specialist but highlighted that adequate time is also needed for such education. Time is not always afforded to the nurse specialist, particularly if the in-patient stay was reduced, as a consequence of the enhanced recovery programme (Thorpe et al, 2014).

Chapple et al (2006) explored patients' experiences of being or becoming terminal ill. Focusing on patients' perceptions, the aim of the study was to evaluate services, and improve quality of care. A total of forty-one patients were interviewed and generally patients valued the work of specialist nurses, in particular advice on practical matters, information giving, emotional support, symptom control and help with communication. However, some patients were distressed that a specialist cancer nurse was involved in their care at such an early stage, discussing topics such as death and dying when deemed 'too early'.

Some felt their emotional needs were not met, offering a rationale that they themselves might be in denial regarding the notion of dying. They also suggested

that it could be difficult for nurses to raise issues relating to dying especially if time was short. This suggested that opportunities and/or cues had been missed for such conversations to take place. The authors concluded that although specialist palliative care nurses were highly valued by those with a terminal illness, stereotypical misconceptions of the term palliative care remained as palliative care continued to be associated with people who were dying.

Danielsen et al (2013b) reported the timing of teaching stoma care and ability to receive new information was critical to the success of independent stoma care. In their study, they quoted participants who found it hard to retain and understand the information provided. Information needs change and nurses needed to provide information that was useful for the evolving patient experience. This was illustrated in a patient narrative which stated,

“It (the stoma) felt like I could never imagine before I had it. And in the end when I had it, I could much better understand things.....” (Danielsen et al, 2013b, p410).

This finding was not discussed in any depth but does illustrate the importance of timely conversations which are likely to change depending on patient need. If this engagement is timely, it has been shown to improve patients’ knowledge, experience and satisfaction with their health care (Patient Information Forum, 2013).

Thorpe et al (2014) mirrored these findings, reporting that patients had no control over the level of support they received to help them gain the confidence in the practical skills of stoma care. Some described having to deal with their stoma when

they did not feel ready to learn and therefore felt unable to fully engage in such learning opportunities. This study also pointed to the importance of sufficient time to retain information, particularly with current healthcare pressures and patient recovery programmes. The adequacy, accuracy and consistency of information given by healthcare professionals to facilitate self-efficacy in stoma care were seen as critical to the patient's recovery. Open and timely communication facilitated a greater sense of control, understanding and the ability to set achievable recovery goals (Thorpe et al, 2014).

Using a phenomenological approach, Kvåle (2007) identified that cancer patients did not always want to talk about their feelings or discuss difficult emotions regarding their disease and future. Interviewing twenty patients with a known cancer diagnosis, emerging themes alluded to avoidance and distancing, normalisation and support from friends and family. Conversations relating to daily life seemed to help them find meaning in life, to feel normal and to support their optimism as an aspect of coping and maintaining hope. Participants did however, want the opportunity to talk about their emotions but they themselves wanted to choose to whom and when. Identifying patients' communication needs was seen to be very important in a therapeutic relationship requiring the specialist nurse to be emotionally aware. In both these accounts (Kvåle, 2007, Thorpe et al, 2014) there is a sense that specialist nurses need to be in tune with the needs of their patients in order to gauge what information to tailor and when.

Tarrant et al (2008) used a mixed method approach to explore whether those with prostate cancer who had seen a specialist nurse had different experiences of information provision to those who had not. Two key features of the study were the availability of the specialist nurse to the patient and the ability of the specialist nurse to liaise between the healthcare system and the patient. Timing of the specialist nurse-patient consultation was deemed crucial. One patient described seeing the specialist nurse immediately after being given the diagnosis and felt that this was too soon, as he was still in shock following the diagnosis. However, another described how the specialist nurse had been sensitive to his shock of diagnosis and had given him time to come to terms with the diagnosis. This infers gauging the mood and assessing the clinical situation is a specialist skill required of the specialist. For those with no specialist nurse input, gaps in their care were experienced; in particular, a lack of time to talk things over following their diagnosis and lack of immediate access to advice and support during their treatment plan. The role of the nurse specialist was important in giving patients the opportunity to talk to a healthcare professional that could answer their questions and address their needs (Broughton et al, 2004).

3.4.5 Efficacy of the specialist nurse's knowledge, skill and aptitude

Specialist nurses play a key role in providing individualised emotional and practical support that is required following surgery. In addition they assist patients to utilise their individual strengths and positive coping strategies to fully attain the improved quality of life that an operation is intended to promote (Allison et al, 2013). They are often perceived as the lynchpin of high quality patient focused care (Chapple et al,

2006, Ream et al, 2009). The importance of specialist skills and knowledge amongst specialist practitioner was presented in the previous chapter and was also evident within this review.

O'Connor et al (2010) highlight how the specialist nurse was the main source of information for patient undergoing surgery for cancer of the rectum. As previously highlighted the aim of their quantitative study was to explore information needs of patients with cancer of the rectum. Information requirements were found to differ slightly with more information needed regards treatment plans, outcomes and preferences as to the type of information needed indicating the diverse nature of the role in meeting the patients' information needs.

Variations in the role of specialist nurse were evident, even within the same speciality (Reed et al, 2007, Ream et al, 2009, Norton et al, 2012, Leary et al, 2014). It was difficult to determine whether this is the diversity of the disease associated with the speciality, the characteristics and skills of the specialist nurses themselves or the structure of the organisation employing the specialist nurse (Reed et al, 2007, Trevatt and Leary, 2010, Leary et al, 2014). This theme highlights the diversity and complexity of evaluating the role of the specialist nurse.

Boot and Wilson (2014) explored challenges faced by specialist nurses when facilitating advanced care planning conversations in end of life care were explored

with the aim of informing education preparation and skill development. Within their qualitative study they sought to understand experiences and perspectives of specialist nurses, through face-to-face interviews. A total of twelve community based participants were purposefully selected. Following an inductive analysis, two significant themes were revealed; balance and risk. The participants felt opening up difficult conversations with patients led to an element of risk, requiring courage. In turn, this led participants having to weigh-up and balance multiple opposing issues before and during the process. The metaphor of tightrope walking was evoked. A range of challenges were raised by the participants including timing, sensitivity, watching for and responding to cues, harming or helping the patient and facilitating/directing conversations. Although participants recognised the challenges brought about by difficult conversations they were also aware conversations such as these were integral to their role. From an educational point of view, they described the need for skills in building therapeutic relationships and actively listening to patients allowing the nurse to truly understand the information needs of the patient.

Nurse-led counselling was shown to improve patient health related quality of life in Smith et al (2002) study, analysing the impact of a specialist service for people living with inflammatory bowel disease. An RCT was undertaken using three validated tools on a controlled and active group in order to measure the outcome of a nurse-led non-validated counselling package. The tools were Disease Activity Score, SF-36 and the Hospital Anxiety and Depression Scale (HADS). The nurse-led counselling package consisted of information provision (information booklets and patient

support group) and psychological intervention (adapted stress management programme teaching coping mechanisms and relaxation). Patients within the control group who had Crohn's disease were found to have lower mental health status, reduced social activity scores and significantly more anxiety and adaption difficulties. Health-related quality of life improved in the control group at six months, irrespective of disease activity but were not sustained for 12. This study highlights the significance of long term follow-up care, suggesting specialist practice needs to develop therapeutic relationships to aid patients in the development of strategies for long term psychological care in chronic health.

Dowling (2008) suggested a close bond with patients was unavoidable if the specialist nurse is to develop a therapeutic relationship. Exploring the meaning of nurse-patient intimacy in cancer care, Dowling (2008) argued that it is only nurses who are self-aware can truly engage in therapeutic relationships with patients. The nurse participants demonstrated this in the study through self-disclosure and the development of a professional friendship. Disclosing personal information to patients had been found to help develop a trusting relationship between the nurse and patient (Davis, 2005) however, differing levels were reported (Vancouver et al, 2001). Participants in the study reviewed, revealed they measured their disclosure by not disclosing too much and being selective in what they felt was appropriate (Dowling, 2008) highlighting the balance of professional boundaries (Morse, 1991, Vancouver et al, 2001). In the paper this balance was illustrated by two participant's narratives;

"I think it's trusting, I think it's good to be open but not too open. Like you have to be careful as well". (Nurse 23, p325)

and

"It's difficult to know when somebody is over involved because what for one nurse is a relationship that they can cope with may be over involved for another". (Nurse 10, p324)

Such expressions of disclosure by the nurse participants, reflects the level of balance between personal and professional engagement and detachment in a therapeutic relationship. Highlighting the 'emotional work' of Hochschild (1983), this study infers the intimacy associated with knowing patients was charged with a sense of emotional overload with potentially negative consequences for the nurse resulting in burnout and that the patient may become dependent on the nurse.

Gerrish et al (2011) emphasized that specialist nurse practitioners were ideally placed to act as 'brokers of knowledge' facilitating links between evidence and practice. Also referred to as being a 'change agent', this was often an overlooked component of specialist practice (Hamric, 1989). However, little was known as to how specialist nurses made the links between evidence and practice. This was relevant to how knowledge might be transmitted. Referred to as knowledge brokering, Gerrish et al (2011) identified approaches used by specialist practitioners to promote evidence-based practice among clinical colleagues. Using a case study approach eighteen specialist practitioners working in hospital and primary care settings were interviewed, five of which were observed for a day as part of an extension to the original case studies.

Amongst their findings, Gerrish et al (2011) reported specialist practitioners actively engaged in knowledge brokering without realising it. Highlighting an indirect approach, the participants described the need and reliance to educate all involved in the patients' health care but at varying levels. They suggest for the specialist practitioners to achieve this they were required to manage and promote the up-take of knowledge. The authors stated this was achieved by generating different types of information, accumulating it, then synthesizing it for translating and disseminating the specialist knowledge. This would ultimately lead onto clinical problem-solving and facilitating change. This illustrates the complex and multifaceted nature of information exchange highlighting the need for specialist nursing education to equip nurses with advanced skills to achieve this.

Two of the references selected for the review, reported different aspects of the same study (Thompson et al, 2008, Dowding et al, 2009) where the decision-making process amongst heart failure nurse specialist was examined. Dowding et al (2009) reported on the judgement analysis survey and Thompson et al (2008) reported on the qualitative study. Twenty-nine heart failure specialist nurses undertook a judgement analysis survey, where they were asked to make two judgements regarding a patient with a history of heart disease, namely drug titration and referral to palliative care. Cues were provided within the patient scenario to aid clinical judgement of the respondent. Six nurses were observed and twelve interviewed as part of the qualitative analysis.

Despite all receiving the same information, judgements amongst the respondents varied considerably. This was attributed to the differences attached to the importance of information presented. Drug titration was deemed straightforward as it relied on factual information relating to knowledge of the disease and related symptoms with drug therapy, whereas palliative care referral was considered more challenging due to the uncertainty of disease progression. Characteristics and strategies for drug titration were based on guidelines and protocols and discussion with peers, on the other hand, referral to palliative care had an element of intuition induced decision-making as no guidelines were available and although discussion with peers did seemingly take place, more often than not the responsibility of the referral was passed onto someone else. Narratives from the respondents demonstrate this:

Medication decision characteristics/strategy

"..... well each time you see them you have a standard set of questions in your head that you go through, you know, from how are you feeling, how is your breathing, how far are you walking, what are you like at rest, is there any oedema, what's your appetite like and you go through it I'll then go and talk with the Consultant or GP and say I've seen this patient, ECG reads as can we up titrate this beta-blocker?" (New #1 Interview, p1319)

Palliative Care decision characteristic/strategy

"It's the fear that you've got it wrong and that they're not actually dying and they're going to bounce back again, it has happened..... but why should you be scared of getting it wrong, cos people want to know don't they, how long they've got, it's just sometimes it's not possible to say and it's that fear of looking stupid, almost..... so I'll speak to the Consultant to see if there is any more we can do, so partly make sure everyone agrees before going ahead". (Experienced #3 Interview, p1319)

Dowding et al (2009) considered the concept of background and foreground knowledge, suggesting background knowledge relates facts about underlying conditions and diseases in patients and foreground knowledge is seen as the management of knowledge required to perform every day. The suggestion here is that background knowledge diminishes with developing expertise, while the need for foreground knowledge increases (Sackett et al, 2000).

These two studies (Thompson et al, 2008, Dowding et al, 2009) reported no significant differences in clinical judgement between nurses educated to degree, diploma or NVQ level. In contrast, other studies have made links between higher educational levels and better clinical outcomes (Wyatt, 2007, Christensen, 2010) suggesting education leads to increased knowledge and confidence. McGee and Castledine (1999, p1076) have further suggested that advanced nursing is a 'state of professional maturity, where practitioners are pioneering innovators and developers of health care', in essence suggesting higher levels of educational enquiry are a necessity (Por, 2008).

Knowledge plays an important part in the role of the specialist nurse as examined by Lester et al (2014) who explored nurses' knowledge in relation to cancer survivorship. Using an online descriptive survey (RR 31%, n=223) the authors reported gaps in the knowledge of graduate nurses with over fifteen years' experience in cancer care. Majority of nurses reported having knowledge regarding

treatment regimens and subsequent side effects but felt they lacked knowledge in relationship issues, sexuality, emotional support and financial and insurance issues. Survivors of cancer continued to face challenges related to daily activities of living as they continued to adjust to their new way of life (Sun et al, 2013). Specialist nurses were seen to be ideally placed to provide continued support and information to patients. The authors recommend curriculum changes so to fill the deficit of knowledge highlighted in this study.

Howell et al (2014) also noted the extensive knowledge base required of the nurse specialist. In this descriptive study, exploring nurse-patient interactions, the authors observed four specialist palliative care nurses interview 34 patients over a period of several weeks. The specialist nurses were described as senior Band 7, working as part of the same team. Three were described as having extended their qualifications. Reported findings demonstrated the wide-ranging knowledge required of the nurses' enabling them to respond independently to the fluctuating needs of patients they encountered, particularly among those with advanced disease, multi-morbidity and frailty.

Emphasis was also placed on the need for good communication skills, suggesting knowledge is only of value if it can be translated appropriately and understood by patients. Studies have highlighted possessing theoretical skills and competencies did not always reflect emotional ability and for a successful therapeutic relationship a balance of both are required (Freshwater and Stickley, 2004, Kooker et al, 2007).

Other studies considered personal attributes, attitudes and beliefs (Kautz et al, 1990, Palmer, 1998, Reed et al, 2007) as crucial foundations for a self-aware, empathetic practitioner equipped to manage their own and other's emotional and to work at an advanced level practitioner (Benner, 1984, Salovey and Mayer, 1990, Freshwater and Stickley, 2004).

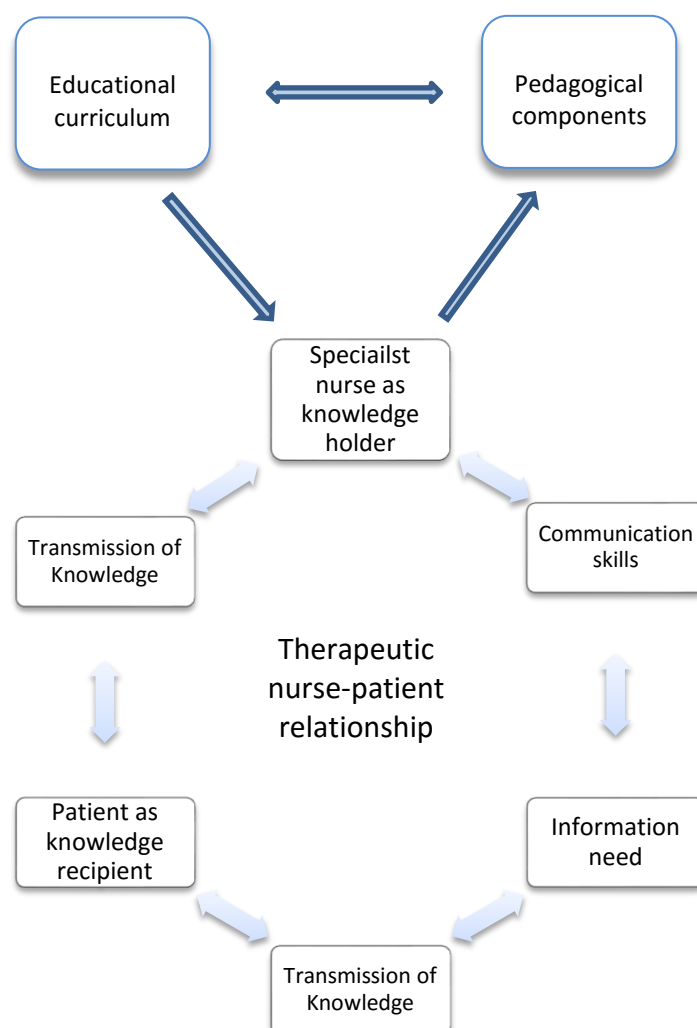
3.5 Conclusion

This chapter has considered the two connecting features of this study; the patient experience and the transmission of specialist knowledge. The therapeutic relationship between patients with a stoma and the specialist nurse providing care is fundamental to assist the adaptation to and acceptance of the profound changes stoma surgery is reported to bring. As highlighted within this review, the quality of this relationship is largely determined by the knowledge and skills of the specialist nurse and timely manner of information giving.

This literature review found insufficient attention has been afforded to the adaptation needs of patients undergoing stoma surgery. Literature has indicated the specialist stoma care nurse has a central function to facilitate giving support and information to patients with stomas. This includes having an understanding and gauging, from the patient perspective, the current need. This ability to understand, addresses patients' needs for tailored information, views the patient as a whole and enhances the therapeutic relationship. However, evidence highlighted in this review suggests the ability to achieve this varies amongst specialist nursing practice.

The need for a comprehensive knowledge base is acknowledged but has little consequence if not transmitted in a manner appropriate for the patient to grasp. How knowledge is transmitted through clinical-based learning is a previously unexplored area and is the key feature of this study (Figure 3.1). Evidence from the review suggests the skills required of the specialist nurse but there is little indication as to how this can be achieved. This raises two questions, does specialist nurse education currently equip nurses for specialist practice and if so is education certain of the pedagogical components of specialist practice.

Figure 3.1 – Key features of the study



4. Pedagogical components of specialist nursing practice

4.1 Introduction

This chapter explores what is currently known about pedagogy for specialist nursing. Pedagogy refers to the nature of knowledge, that is, what is taught and how it is taught (Earle and Myrick, 2009) as well as other aspects of teaching and learning such as content and information, skill acquisition, cognitive skills and interpretation (Ironsides, 2001, Chabeli, 2008, Horsfall et al, 2012, Zakari et al, 2014). Consideration of these aspects was essential to building an understanding of specialist practice in the context of educational theory and practice.

4.2 Nature of knowledge

Walker and Advant (2004) propose knowledge is the product of knowing as it is both experiential and summative, suggesting it is collected from learning experiences over time. However, knowing something does not necessarily mean that what is known is understood. For example, a nurse working within the field of gastroenterology will be familiar with monitoring urine sodium and weighing patients with intestinal failure as a basic clinical skill. Some might view this as a nursing task but it becomes a clinical skill when an understanding why and acting upon the results takes the depth of knowledge to a greater appreciation of the actual patient care required.

In a qualitative study, Mantzoukas and Jasper (2008) reported five distinct types of knowledge existed in nursing; personal, theoretical, procedural, cultural and reflexive. Their findings were based on a secondary analysis of an original

ethnographic study and interpreted, classified and indexed the types of knowledge used by nurses to care for hospitalized patients. Such types of knowledge are seen elsewhere in the literature (Carper, 1978, Benner, 1984, Eraut, 2000) and create a foundation for nurse education.

Two different dimensions to understanding the nature of knowledge are also considered in the literature: knowledge as product and knowledge as process (Manley, 1997, Graham et al, 2006, Chinn and Kramer, 2011). Knowledge as product refers to knowledge as facts and information (Chinn and Kramer, 2011) and is objective (Manley, 1997). Whereas, knowledge as a process refers to the understanding of an experience (Chinn and Kramer, 2011) and so is subjective in nature (Manley, 1997). Horsfall et al (2012, p930) refers to this as 'the sophisticated nature of knowledge', which is beyond unequivocal facts or data. It is perhaps both as knowledge does not just consist of facts and information but also includes interpretation, experience and understanding, a level of knowledge and ability referred to by Benner (1984) and Mantzoukas and Jasper (2008) as expert.

Chinn and Kramer (2011) suggest that in a human science such as nursing, it is necessary for formal, scientific, informal and subjective knowledge to contribute to the body of knowledge in the discipline. It can be argued that within the field of stoma care nursing, nurses encounter patients who have the burden of chronic and/or life-threatening disease with the unique psychological and practical challenges that stoma surgery brings. Knowledge, experience and understanding for nursing practice in this situation cannot be based on formal scientific knowledge

alone. Therefore, knowledge can also be seen in yet another dimension, associated with action and decision-making and aligns closely to 'patterns of knowing' (Carper, 1978). Carper's work sets out to bring together the ways of knowing that are pertinent to nursing, integrating both practical and theoretical knowledge.

Carper (1978) identified four patterns of knowing. The first, empirics, refers to the science of nursing and was 'empirical, factual and descriptive' (Carper, 1978, p15). The second is aesthetics, the art of nursing. This includes list of attributes such as appreciation of the patient experience and holistic care. Personal knowledge relates to an awareness of self and finally, ethics is concerned with the moral knowledge of nurses, specifically focusing on 'matters of obligation or what ought to be done' (Carper, 1978, p20). In essence, these four patterns are all valid and essential elements for advanced practice and need some thought for educating the level of specialist practitioner.

Benner's influential theory of nursing expertise closely follows the skill acquisition theory developed by Dreyfus and Dreyfus (1986). It proposes that the journey from 'novice' to 'expert' encompasses five stages. In the 'novice' stage, beginners learn through instruction and acquired specific facts, features and actions. An important aspect of this stage is that the rules that novices learnt are free from circumstance, which although allowing for specific facts, features and actions to be learned also offer room for flexibility and therefore limited performance activity.

Having developed an understanding, the novice moves onto the 'advanced beginner' stage. At this stage individuals start to use and make sense of the information provided and soon move towards the 'competent' stage. Here, the individual not only makes sense of the situation but begins to organise their actions in terms of what is most important. This stage sees an increased level of efficiency, although planning is still conscious it can be both concrete and abstract.

In the 'proficiency' stage, situations are perceived as a whole, rather than as unconnected aspects, and certain features are perceived as significant whilst others are ignored. Here the individual demonstrates ability to organise and understand problems intuitively but still requires analytical thinking to choose an action. Finally, at the 'expert' stage the individual demonstrates a deep understanding of the situation. Acting naturally, they are insightful, intuitive, and creative, making decisions and solving problems explicitly.

The stages of transition from novice to expert are clearly identified within Benner's (1984) theory and highlight how knowledge and skills are acquired over time. These stages are often referred to in nursing practice and education. Each stage is acknowledged but there appears to be no guidance as to how to achieve each transition or how a nurse transfers from one stage to another. So whilst it provides a framework that supports lifelong learning for nurses that is applicable to practice and education, practitioners and educationalists are left to consider how to fill the gaps.

Within a religious education context, Bourdieu's (1977) ethnographic observations, equates reasoning with a discrepancy between theory and practice in that people are often not conscious of the logic of their practice. He calls this 'learned ignorance' and goes on to suggest that people's practices are similar to playing games. 'A player is not always conscious of the rules and principles of the game but can develop strategies to play the game well' (Bourdieu, 1977, p101). This relates well to Benner's (1984) theory of skill acquisition in nursing and Carper's (1978) patterns of knowing, particularly as the differing elements of knowing do not exist in isolation or mutual exclusion of each other, but with significant overlap.

The work of Carper (1978) and Benner (1984) have been very influential in their attempts to explain nursing knowledge but have also been criticized. Both present their theories in a linear manner and in the form of objective and subjective ways of knowing. They both argue there are unique and multiple types of nursing knowledge but disagree about what these types of knowledge share. This has led to some criticism of not doing enough to integrate the various types of knowledge (English, 1993, Mantzoukas and Jasper, 2008, Chinn and Kramer, 2011) and also creates a need for further exploration as to the explicit nature of nursing knowledge, and in particular pedagogy.

Eraut (2000) proposed two distinct elements of knowledge; knowledge embedded in routines and protocols and knowledge that are explicitly needed at the time, intuition. Such knowledge might influence how the patient is assessed, what decisions are made and/or how the nurse interacts with the patient. Returning to

the work of Mantzoukas and Jasper (2008), they reported nurses to be consciously aware of using different types of knowledge in complex situations allowing them to prioritise care based on their clinical judgement. These concepts capture the development of proficiency and expertise as described by Benner (1984) and mirror the knowledge and skills required of the specialist nurse. This suggests knowledge is key as it raises an awareness of personal and professional accountability and the dilemmas of practice. It therefore evolves through a combination of skill, expertise and ability but as Halpern (2014) suggests it is only influential once meaning has come from it.

4.2.1 Knowledge and thought

In order to make sense of new information, existing knowledge is retrieved and used when new knowledge is received (Ceci, 2004). Some authors consider nurses to be more adept at this than others (Burnard, 1997, Freshwater and Stickley, 2004, Gianotten et al, 2006, Kooker et al, 2007). Salovey and Mayer (1990) proposed that some individuals possess greater ability than others to reason about and use emotionally intense information to enhance both cognitive activity and social functioning. Recognised as emotional intelligence, Mayer and Salovey's (1997) theoretical framework offers a four branch model; ability to perceive, use, understand and manage emotions.

The concept of emotional intelligence was initially developed by Mayer et al (1990). Emotional intelligence combines emotion with intelligence resulting in the ability to

use emotions as a support in problem-solving and decision-making. Although several theories have been proposed, the three theories of Mayer and Salovey (1997), Bar-On (1997) and Goleman (1998) have influenced nursing the most. Each conceptualized emotional intelligence in relation to their research and as a consequence, defined emotional intelligence as an ability (Mayer and Salovey, 1997), a set of traits and abilities (Bar-On, 1997) or a combination of skills and personal competencies (Goleman, 1998). Emotions are not easy to translate especially for those experiencing them. To be emotionally intelligent is generally described as a 'core aptitude related to one's ability and capacity to reason with one's emotions, especially in relation to others' (Freshwater and Stickley, 2004, p92). Such insight is said to 'solve emotion-laden problems and regulate behaviour' (Salovey and Mayer, 1990, p186).

The significance of emotions in nursing is recognised in the literature (McQueen, 2004, Freshwater and Stickley, 2004, James et al, 2010, Bailey et al, 2011) and the influences on direct patient care are acknowledged (Smith, 1992, 2012). McConnell and Eva (2012) reported that both positive and negative emotions also play an important role. More specifically they suggest emotions influence how individuals identify and perceive information, how it is interpreted and how they might act as a result of the information available at the time.

Ajzen and Fishbein (1980), however, took to exploring and understanding individual's complex, decision-making processes, resulting in the Theory of Reasoned Action. According to the theory, there are two types of beliefs; behavioural and

normative. Behavioural beliefs are an individual's assumption that certain behaviour will lead to certain results. In other words, the individual assumes that if they act in a certain way this will have certain results, to which they attribute a certain value. Normative beliefs reflect an individual's subjective evaluation of how 'significant' others would wish them to act in order to perform or avoid a specific behaviour, considering their motivation to act as they wish to. An individual's intention to act in a certain manner is affected by two main factors; their attitude towards the behaviour and subjective norms. Behavioural attitudes stem from the individual's judgement whether performing the behaviour would be 'good' or 'bad' for them. Therefore, attitudes are a function of the individual's beliefs concerning the personal result expected to follow from realization of their intentions. This subjective norm is the individual's personal perception of the positive or negative social pressures exerted on him or her to perform or avoid certain behaviour. A person who believes that 'significant others' support certain behaviour will perceive the social pressures as supporting behaviour and vice versa. Thus the subjective norm applies pressure facilitating performance or avoidance of the behaviour independently of the individual's attitude towards this behaviour.

The Theory of Reasoned Action (Ajzen and Fishbein, 1980) most frequently relates to health education and considers behavioural changes to individual's lifestyle.

However, an extension to the conceptual framework explored perceived emotional control and indicated that a person's motivation is influenced by how difficult the behaviours are perceived to be, as well as the perception of how successfully the individual can, or cannot, perform the activity. This has potential relevance to how

specialist knowledge and skills are translated to stoma patients. Nurses acknowledge the need to address issues relating to adaptation as a feature of their role yet sources in the literature implies this is not the case (Reynolds and Magnan, 2005). This infers that if a specialist stoma care nurse perceives themselves not to possess the skills to address adaption related issues with stoma patients, this will affect their behaviour, causing them to consider the implications of their actions, i.e. whether or not to engage in such conversations, with a likely result of them avoiding such clinical situations. Conversely, if the specialist nurse perceives to have the belief of confidence in such conversations, they are then more likely to be facilitative, with little hesitation.

Mayer and Salovey's (1997) emotional intelligence theoretical framework has an essence of Ajzen and Fishbein's (1980) the Theory of Reasoned Action highlighting the importance of what is initially 'perceived' suggesting a requirement of self and emotional awareness. Self-awareness and regulation of emotions are skills that contribute to the professionalism of nursing (Burnard, 1997). These attributes, which are encapsulated in emotional intelligence, enable individuals to cope more efficiently in complex situations, contributing positively to holistic patient care (McMullen, 2003). These attributes were consequently found to be of critical importance in the analysis of the challenges faced by the stoma care nurses in this study in using specialist knowledge and skills to facilitate the adaptation needs of the patients.

4.2.2 Knowledge translation

Consideration is given now to knowledge translation as it is evident that knowledge alone does not change health care outcomes for patients (Gibson et al, 2001, Caress, 2003). From the patient perspective, they may not appreciate the relevance of the information or find it too complex. They may also be overwhelmed by information in a situation of stress and anxiety. There may also be an element of disbelief and choice about ignoring or acting on information. Effective knowledge translation between the specialist nurse and patient is not therefore straightforward and requires pedagogical processes.

Advanced practitioners can assume they translate theoretical knowledge into practice (Kotronoulas et al, 2009). However existing critiques illustrate this is not necessary the case (Eccles et al, 2005, Doane and Varcoe, 2008, Metzler and Metz, 2009, Duhamel, 2010, RCN, 2010a). There appears to be a complex interplay of the content, process and context for learning and practice in both the classroom and clinical setting (Doane and Varcoe, 2008, Kotronoulas et al, 2009), which if inclusive has the potential to draw practice closer to education (Kotronoulas et al 2009).

Pedagogy therefore needs to navigate a gap between theory and practice or a gap between theory and translation (Roskell et al, 1998).

4.3 Gap in knowledge or gap in translation

The literature alludes to differing elements of the theory-practice gap; educational theory and practice (Bendall, 1976, Roskell et al, 1998, Landers, 2000), clinical theory

and practice (Proctor and Reed, 1993, Roskell et al, 1998), research theory and practice (Dickson, 1996, Roskell, et al 1998) and professional operational theory and management practice (Rafferty et al 1996, Proctor and Reed, 1993).

Prior to nursing becoming a graduate professional much of the emphasis of the theory-practice gap related to new knowledge generated through research, bearing little relationship to the reality of practice experienced by practitioners (Roskell et al, 1998). Now that nursing is an entirely graduate profession (NMC, 2008, 2015) this issue is predicted to reduce as registered nurses are encouraged to engage in research activity having acquired the basic skills of research, ensuring their clinical practice remains evidence-based. However, Allmark (1995) and Rafferty et al (1996) emphasize that the complexity and variability of practice has not been taken into account sufficiently, which in turn prevents the student from making a relationship between theory and practice for themselves.

In terms of the discrepancies between what research evidence demonstrates and what actually occurs in practice, some authors have argued that this is the crux of the theory-practice divide (Roskell et al, 1998, McKenna, 1997, Timpson, 1996). The use of philosophies, models and theories act as guides for nursing practice and just as clinical practice influences the development of theory. Both are critical to the development of nursing knowledge (Alligood, 2005). The critical translation element however appears to depend not on the familiarity with theoretical components of practice but on the competency of individuals to apply them.

Nursing concepts have changed to accommodate an ever-changing healthcare system, with more emphasis on integrated care, holistic approach and transparency (Pavill, 2011, Frances, 2013). Benner et al (2010) call for a radical transformation in the way nurses are currently educated suggesting a need for a sophisticated understanding of the biological, psychosocial and cultural needs of patients. Sullivan and Rosin (2008) suggest nursing is a blend of science and technology with the art of caring and compassion. A knowledge base, as such, needs recognition for specialist practice.

Complexities in patient care are becoming increasingly challenging as healthcare practices change (Mason, 2011) leading to the change in the pace information is given (Taylor, 2001). This highlights the increasing importance as the quantity of relevant information which could, as well as should, be imparted has increased but the time available to offer it has decreased (Taylor, 2001). Argued earlier in this chapter some specialist nurses appear more able than others to translate their specialist knowledge and skills to patients. An emphasis on insights into one's own and other emotions, described by the ability model of emotional intelligence (Mayer and Salovey, 1997), offers an explanation for this.

4.4 Different ways of knowing

Incorporating Carper's (1978) patterns of knowing, Johns (2000) suggests guided reflection as an additional pattern of knowing. The use of reflecting on experience as a means of enhancing clinical practice stems from the work of Schön (1983). Reflective

and critical thought can help reason prejudices ensuring a growing awareness through reflective critical thought with regards the nature of knowledge so not to assume things are true when they simply are not (Paul and Heaslip, 1995). Benner (1984) points out that not all knowledge embedded in expertise can be captured in theory and furthermore believed nurses needed emotional space to think and feel about their practice (Benner and Wrubel, 1989). Reflective practice allows them to explore the emotions that engaged or involved them in the situation, in the first place. Reflection can be described as the ability to explore one's own actions, thoughts and feelings, and think purposefully to gain new insights, ideas and understanding (Newell, 1992).

Several authors have identified critical inquiry, engaged dialogue and reflective practice as essential to experiential learning (Johns 2000, Kolb and Kolb, 2005, Boyer et al, 2006) with opportunities for reflective learning facilitating cognitive, affective and moral development (Johns, 2000, Strain, 2005). Without such reflection learning is not sustainable (Shapiro and Reiff, 1993). In a longitudinal study, Hayward et al (2013) explored reflective practices amongst physiotherapists. Their findings indicate how reflection offered individuals the ability to reconstruct their experiences, analyse and make sense of their experience and create a personal and deeper understanding of that experience. The development of critical thinking and meta-cognitive skills were seen as particularly important outcomes for the physiotherapists who participated in this study, for them to apply their learning experiences.

As already indicated specialist practice is dedicated to delivering holistically planned and therapeutic patient care where personal knowing is considered integral (Freshwater, 2007) as what is disclosed within the nurse-patient relationship becomes the basis for knowledge. Jacobs (1998, p25) viewed 'personal knowing as the most problematic and difficult pattern to master and teach'. Personal knowing can be acquired through the therapeutic use of self (Currid and Pennington, 2010). This application of self promotes integrity and wholeness in personal encounters with patients and other healthcare professionals. By creatively blending personal knowing with empirical, aesthetic, ethical and socio-political knowledge (Carper, 1978), nurses can learn to perform within a therapeutic caring culture that is holistic and significant to the patient's condition and recovery and extend this to include their families (Holmes & Gastaldo, 2004).

Munhall (1993) identified 'unknowing' as a further component of knowing, suggesting this is an awareness that the nurse does not and cannot know or understand the patient when they initially meet. The skill of recognising this unknowing ensures the nurses remains alert to the patients' perception of need. This echoes Mayer and Salovey's (1997) theoretical framework of emotional intelligence, where on initial meeting with the patient, the nurse 'perceives' the situation by tuning in to their own self and emotional awareness and that of the patient in order to gauge the need of the situation. Part of this awareness is sometimes referred to as intuitive or tacit knowledge; just knowing and understanding common thoughts.

According to Polanyi (1966) when we use our intuition we filter information initially triggered by the imagination which leads us to integrate the information and knowledge to solve the problem. Inherent in intuition is tacit knowledge which is highly relevant to knowing (King and Clark, 2002, Billay et al, 2007, Green, 2012). The experience of knowing for specialist stoma care nurses is an encounter in which they become aware of an impending clinical situation before it occurs and with no conscious understanding as to why they know what they know. This type of practice evolves through experience, during which time new knowledge and experiences are embraced, a considered feature of expert practice (Benner, 1984). The nature of this experience is complex as there appears to be a process of acquiring and acknowledging the features required to practice at this level. Qualitative data coincides with this perspective suggesting maturity and life experiences are additional factors, which transform perceptions, beliefs and practice (Brown, 2012). Such knowledge contributes to the development of intuitively knowing.

The elements of self and emotional awareness, insight and intuition, gauging the mood and tuning into the patient need begin to illustrate the tools needed for knowing the patient in order to facilitate care in nursing and what might be reflected within the pedagogy for specialist practice.

4.5 Tools needed for knowing

Knowing the patient is an essential component of nursing practice, central to the process of care and the nurse-patient relationship and demonstrates expertise in nursing practice (Tanner et al, 1993, Peden-McAlpine and Clark, 2002, Morrison and Symes, 2011, Zolnierrek, 2014). The study by Bundgaard et al (2012) illustrates through an investigation of what knowing the patient meant in an endoscopy clinic. These authors identified two themes: what to know and how to get to know. Nurse's information focused on practical issues related to the endoscopic procedure. Categories of necessary knowledge included anxiety, medication and previous experience. Nurses were reported to have uncovered the necessary information to 'get to know' their patient by using their senses and communication skills. These reflect the characteristics of emotional intelligence as stipulated by Mayer and Salovey (1997) (See Table 6.7), whereby skills and abilities such as self and emotional awareness, emotional self-control, empathy, comprehensive interpretation of language, active listening, tuning into and picking up on patient cues, verbal and non-verbal behaviours, intuition, clinical reasoning, clinical judgements, problem-solving and reflection all play an important role in getting to know the patient, develop a therapeutic relationship and facilitate the patients' needs.

4.6 Developing expertise

As Benner (1984) has demonstrated elements of expertise can be achieved at various stages of nursing practice. Scholes (2006) indicates how expertise is constantly evolving with aspirations to achieve it inspires and energises. Jasper

(1994) infers that expertise is a relative condition that confers and confirms that an individual has the attributes, skills and knowledge at a higher level than another. Specialist nurses by their nature are expected to be at the leading edge of developing innovative practice and seen to act as change agents and therefore inspire practice (Hamric, 2014).

Conway (1996) argues that expertise can be categorised as four types of expertise; technologist, traditionalist, specialist, humanistic existentialist. Role development has changed significantly since this work was undertaken and it might be considered that nurses demonstrate expertise in more than one domain today especially when working to a broad range of competencies or multiple sub-roles as seen in specialist practice. Within specialist stoma care nursing there is an expectation for the nurse to demonstrate technical expertise within a holistic model of care. This is in contrast to a less experienced nurse who may have the technical ability without necessarily having the depth and breadth of knowledge and expertise to make informed decisions beyond a very focused sphere of practice. The use of many forms of knowledge to inform critical thinking, clinical reasoning, clinical judgement and decision-making within specialist practice illustrates Mayer and Salovey's (1997) emotional intelligence theoretical framework.

4.7 Conclusion

This chapter considered a pedagogical perspective of specialist nursing practice. Together with Chapter 2 (context of specialist nursing practice) and Chapter 3

(critical appraisal of the literature pertaining to two connecting features of the study, the patient experience and the transmission of specialist knowledge and skills with particular emphasis towards adaptation) the pedagogical perspectives indicated the need for the exploratory study to determine patients' needs and clinical nurses specialists articulation of the challenges in meeting these needs.

Given the complex nature of adaptation and the need for the specialist nurse to possess highly specialised knowledge and skills of facilitation, a theoretical framework was required to explain and simplify what is occurring in specialist stoma care practice. This was informed by the emotional intelligence theoretical framework of Mayer and Salovey (1997). The next chapter explains how and why a qualitative research method and a phenomenological methodology contributed this framework to achieve the study's aim and objectives.

5. Methodology and methods

5.1 Introduction

The critical appraisal (See Chapter 3) highlighted how the specialist nurse needs to modify and deliver information to patients in a way that they understand, the success of which partly depends on the particular skill set of the individual nurse. A comprehensive knowledge base is acknowledged but has little consequence if not translated in a manner appropriate for the patient to grasp. There is evidence of what is required of the nurse but insufficient awareness of the educational elements of specialist practice (Sirota, 2006, Simmons et al, 2007, Kotronoulas et al, 2009, Ang et al, 2013, Danielsen et al, 2013a). A knowledge base needs to be fostered to equip and support the nurse to become confident and competent in clinical practice. Current literature reveals a positive relationship between education and practice whilst advocating the need to improve education (Waterhouse and Metcalfe 1991, Booth et al, 1996, Sirota, 2006, Simmons et al, 2007, Kotronoulas et al, 2009, Hoekstra et al 2012, Dyer and das Nair, 2012, Danielsen et al, 2013a). However, what is less clear is the content and structure which informs educational delivery. How knowledge is transmitted from clinical based learning is a key feature of this study. In two phases, this study will explore the role of the specialist stoma care nurse in facilitating the adaptation of patients following stoma surgery and inform nurse education.

This chapter establishes the philosophical underpinnings and theoretical assumptions upon which this study was built and demonstrates the relationship

between the research inquiry and the methodology. First, the aim and objectives of the study are presented. Following this the research design for both phases of the study are addressed, including the selection of the sample and sampling methods used to meet the aim and objectives. Consideration is then given to the methods selected for the data collection at each phase. This in turn establishes a foundation for assuring quality and trustworthiness and offers insight to working imaginatively with the data and findings. The role and influence of the researcher in both data collection and analysis is considered, as to, the ethical implications in relation to the principles of the methods used.

5.2 Aims and Objectives

5.2.1 Research aim

To identify the knowledge and skills required by the specialist stoma care nurse to facilitate the needs of patients adapting to a newly formed stoma to inform specialist nurse education.

5.2.2 Research objectives

- To explore the experiences of patients as they adapt to stoma surgery and identify how this differs from one person to another.
- To create vignettes from the patient's experiences, for specialist stoma care nurses to explore.

- To explore the complexities of transmitting specialist knowledge and skills by the specialist stoma care nurse to facilitate the adaptation needs of the patient.
- To identify the pedagogical components required to prepare nurses for specialist stoma care practice.

At the end of this study pedagogical perspectives of specialist stoma care practice are conveyed.

5.3 Study design

5.3.1 Rationale

Assumptions can be made regarding the needs of someone living and adapting to stoma surgery in terms of their physical and psychosocial well-being, as well as the specialist nurse's ability to facilitate these needs. The many physical and psychological difficulties patients with stomas face on a daily basis have already been detailed. These challenges continue to be reported (Thomas et al, 1987a, Thomas et al, 1987b, Kelly, 1992, White and Hunt, 2002, Danielsen et al, 2013b, Thorpe et al, 2014). An awareness of how specialist stoma care nurses facilitate these challenges can offer a pedagogical perspective and inform nurse education based on a valid pedagogical premise.

The choice of research methodology for phase one was informed by the objective of affirming a detailed understanding of the patient's experience of living with a stoma and to create the vignettes for phase two. To enable a meaningful understanding of these experiences, a qualitative approach was used. Qualitative methodologies offer a holistic approach to research as they set out to capture the experiences of human beings in all their complexities in any context, and is neither statistically driven nor do they seek to support or defend a hypothesis (Silverman, 2006, Denzin and Lincoln, 2011, Creswell, 2012). Adopting a qualitative approach allows patients to identify needs from their perspective (Holloway and Wheeler, 2010, Parahoo, 2014). The focus of this study was to explore patient experiences as they adapt to the profound changes brought about by stoma surgery to inform specialist education. Conducted in two phases, this study initially explored such life experience using an interpretive phenomenological methodology. In preparation for phase two, vignettes were created from the patients' narratives. Applying a focus group methodology, the vignettes formed a stimulus for discussion by specialist stoma care nurses for phase two of the study.

5.3.1 Qualitative methodology

Qualitative methods are concerned with the naturalistic description or interpretation of phenomena in terms of the meanings these have for the people experiencing them (Cohen et al, 2000, Sandelowski, 2004, Redmenon and Curtis, 2009, Creswell, 2012, Parahoo, 2014). The inductive and flexible nature of qualitative data collection methods offers unique advantages (Streubert and Carpenter, 2010, Parahoo, 2014),

the biggest of which is the ability to probe into responses or observations as needed and obtain more detailed descriptions and explanations of experiences, behaviours, and beliefs (Morse and Field, 1996), offering a deepness and a richness to the data collected.

This study uses a naturalistic, interpretive approach, to elicit personal and authentic data. Whilst the study is placed in both the patients' and specialist nurses' setting, 'it attempts to make sense of, or to interpret, phenomena in terms of the meanings people bring to them' (Denzin and Lincoln, 2011, p3). In this instance, an interpretation of the adaptive journey following stoma surgery was considered of individual patients.

Qualitative research seeks to understand people's perceptions and motivations, capturing the language and imagery of a person's experience. It focuses on 'understanding the whole' (Burns and Grove, 2003, p357) which is in keeping with the therapeutic philosophy of nursing (Leininger, 1985). Qualitative research links peoples subjective lived experiences, perceptions, thoughts and feelings rather than what is objective; that is it explores the whole phenomenon revealed in and through individuals (Crotty, 1996, Cohen et al, 2000). This then, was used in phase one of this study, as it explores lived experiences; capturing a common essential understanding of living with a new stoma as a way to inform specialist nurse education.

Creswell (2012) advised that the type or tradition of qualitative inquiry shaped the design of the study. Hence, prior to determining, phenomenology the most

appropriate method others qualitative methods were considered, namely ethnography and case studies.

Ethnographic research derives from the world of social anthropology where the commitment is the discovery of cultural knowledge (Streubert and Carpenter, 2010) by observing behaviours, thoughts and attitudes of cultural groups (Schneider et al, 2007). Case study research also derives from social anthropology and is seen to explore a phenomenon or several phenomena in context (Holloway and Wheeler, 2010). Adaptation for the patient with a stoma is seen as a complex relationship between acceptance, social interaction and stoma care self-efficacy (Simmons et al, 2007) and not necessarily perceived as certainty. It was felt that neither ethnography nor case study approaches would not adequately allow meanings or 'phenomena', to appear in their fullest breadth and depth, therefore were not able to meet the aim and objectives of the study.

5.3.2 Phenomenology

Phenomenology aims to attain a deep understanding of the nature or meaning of everyday experiences (van Manen, 1990, Beck, 1994, Cohen et al, 2000), by gaining insightful descriptions of the way that the world is experienced. Polkinghorne (1989) suggested that phenomenology explores the structures of consciousness in human experience, meaning how we assemble an awareness of our experiences.

Phenomenology is an integral field of inquiry that intersects philosophical, sociological and psychological disciplines (Beck, 1994, Crotty, 1996) as it serves to 'bring to language perceptions of human experience with all types of phenomena' (Streubert and Carpenter 2010, p29). Crotty (1996, p24) suggests 'learning and understanding people's subjective experiences has an obvious and multifaceted importance', as it allows insight into the lived experience and can therefore reflect on current clinical practice.

The philosophy of phenomenology offers a pre-reflective look at lived experiences which have not been conceptualised or categorised by individuals which are often taken for granted (Lavery, 2003). These could capture a common essential understanding of living with a new stoma. The focus of phase one was patients adaptive experiences of stoma surgery, the challenges they faced and in which ways this may have impacted their daily lives and therefore deemed to be the most suitable and appropriate tradition of inquiry.

Two differing approaches to a phenomenological enquiry exist; Husserlian and Hermeneutic. The Husserlian approach offers a descriptive method where essential and universal structures are found and described (Lavery, 2003, Lopez and Willis, 2004, Holloway and Wheeler, 2010) whilst the Hermeneutic approach attempts to interpret the meaning of the phenomenon in context (Holloway and Wheeler, 2010). Within the Husserlian approach bracketing is used. This is where prior assumptions and preconceptions is seen as important for descriptive phenomenologists but hermeneutic phenomenologists believe that these prior experiences might become

sources of knowledge and sensitise the researcher to the meanings that might be presented in the narratives of the participants (Beck, 1994, Lavery, 2003, Streubert and Carpenter 2010).

Phase one of this study explored patient experiences as they recover from stoma surgery. These experiences are drawn upon during the course of their journey as they adapt to life with a stoma. It was therefore important to ensure the research approach was insightful and illuminated the phenomenon as well as capture its essence. The researcher felt it was near impossible to 'bracket' prior assumptions and experiences having worked within the specialty for over 25 years and therefore chose an interpretative line of inquiry; hermeneutic phenomenology.

5.3.4 Hermeneutic or interpretative phenomenology

Hermeneutic phenomenology has an ontological rather than an epistemological base (Koch, 1995, Lavery, 2003), where understanding is conceived not as a way of knowing but as a mode of being (Merleau-Ponty, 1964). This philosophical position is well suited to discovering understandings and therefore lends itself to this study as its focus is adaptation to stoma formation and pedagogical education and exploring the impact this has on 'being-in-the-world' (Dreyfus, 1986, p124).

Phenomenological methods are particularly effective at bringing to the fore the experiences and perceptions of individuals from their own perspectives, and therefore at challenging structural or normative assumptions (Crotty, 1996).

Utilizing a hermeneutic approach adds an interpretive dimension to phenomenological research and as such goes beyond the mere description of core concepts and essences to look for meaning embedded in common life practices (Lopez and Willis, 2004). The overarching aim of this study was to identify the transmission of knowledge and skills of specialist nursing practice. Interpreting experiences of patients with newly formed stomas as lived enabled the richness of the participants' narrative to be created into vignettes. The vignettes offered meaning to the intensity of daily life in the context of living with a stoma for the participants. Using these as triggers for discussion amongst specialist nurses elicited how they would address the patient issues.

Meanings are not always apparent to the participant but can be gleaned by the narratives they produce. Gadamar (1976) refers to this as 'fusions of horizons', stating one horizon is the narrative of the participant which meets with the knowledge and experience of the interpretative researcher. Any pre-judgements about the subject in question are acknowledged and any interpretations by the participant are valued for the contribution they make throughout the research process (Gadamar, 1976). The researcher's involvement in the making and presentation of the data is made explicit, and rather than being set aside, is added to the participant's interpretations as part of the interpretive process. This is referred to as the 'hermeneutical circle' (Heidegger, 1962, p. 195). Table 5.1 summarizes advantages and disadvantages of this approach.

Table 5.1 - *Advantages and disadvantages of hermeneutic phenomenology (Burns and Grove, 2003, Holloway and Wheeler, 2010, Streubert and Carpenter 2010, Creswell, 2012)*

Advantages	Disadvantages
Always has the potential for a much deeper understanding of people.	Potentially it can be difficult to know when to conclude a study: when does the interpretive process stop?
Well-grounded in philosophy and the social sciences more generally and hence is relatively easy to justify	
It is an approach to analysing interview texts to draw out meaning	

The hermeneutic circle describes the process of understanding a text in an interpretative manner (Holloway and Wheeler, 2010). It refers to the idea that one understands of the text as a whole is established by reference to the individual parts and one understands of each individual part by reference to the whole. Neither the whole text nor any individual part can be understood without reference to one another, and hence, it is a circle (Creswell, 2012). However, this circular character of interpretation does not make it impossible to interpret a text; rather, it stresses that the meaning of a text must be found within its cultural, historical, and literary context (Holloway and Wheeler, 2010) or indeed clinical practice.

5.3.5 Focus group methodology

Phase two of this study explored knowledge transmission and skills of the specialist stoma care nurse with a particular emphasis towards the facilitation of patients to adapt to living with a stoma. Keeping within a qualitative paradigm, focus group methodology was determined an appropriate approach for the purpose of eliciting

how specialist nurses would address the patient issues disclosed within phase one of the study. Focus groups offered the specialist nurses a forum to share their thoughts, feelings, attitudes and ideas; drawing upon both personal experience and professional expertise. This had the potential to offer insight into the pedagogical perspectives of specialist stoma care nursing practice.

Focus group methodology was originally developed on the basis that many consumer decisions are made in a social context and often as a result of discussions with others (Robinson, 1999, Parahoo, 2007). Focus group research often stands alone but also forms a source of data collection within a qualitative approach (Holloway and Wheeler, 2010). Its theoretical underpinnings can be traced to the assumptions of the interpretative qualitative paradigm (Jayasekara, 2012), thus generates new meaning and information from the participants' point of view.

Focus groups are seen as group discussions, conducted to review a particular subject and defined as 'a research technique that collects data through group interaction on a topic determined by the researcher' (Jayasekara, 2012, p411). They can be particularly useful to examine what people think and their views and beliefs about a specific topic (Liamputtong, 2011). The focus group is also a good way of determining why different groups think of things in a different way. They are seen as a useful way of generating knowledge, especially when a particular question requires some discussion. Focus groups bring individuals together with an aim 'to understand and explain, the meanings, beliefs and cultures that influence the feelings, attitudes

and behaviours' (Rabiee, 2004, p655), as summarized in Table 5.2. The first description applies to this study.

Table 5.2 - *Description of focus group methodology (Patton, 1990)*

Focus group methodology is;
<ul style="list-style-type: none"> • Basic research to contribute to fundamental theory and knowledge • Applied research, to determine programme effectiveness • Summative research, to determine programme effectiveness • Formative evaluation, for programme improvement • Action research for problem-solving

Focus groups were chosen as the ideal method of data collection, for phase two of this study, for the sole purpose of eliciting how specialist nurses would address patient issues as emphasized within the themed vignettes developed from the narrative of participants from phase one. Focus groups offered the specialist nurses a forum to share their thoughts, feelings, attitudes and ideas; drawing upon both personal experience and professional expertise. These beliefs and ideas informed the pedagogical components of specialist nursing practice. Conduct of the focus groups is detailed in Chapter 6.

5.4 Sample and sampling strategy

The sample and sampling strategy were purposeful in both phases of the study. This is a strategy commonly used in qualitative inquiry for the identification and selection of information-rich cases related to the phenomenon of interest (Patton, 1990,

Bowling, 2009, Streubert and Carpenter, 2010). In phase one of the study, the patient participants articulated they had undergone stoma surgery and talked about what it meant to them as they were living the experience of having a stoma, as a part of their life. Phase two required nurse participants who were sufficiently qualified to interpret the patients' experience, namely: the specialist stoma care nurse. This was so they could elicit the challenges faced by patients, demonstrate their specialist knowledge and skills in facilitating the patient's ability to adapt and thus highlight the pedagogical perspective for specialist practice. The recruitment process and purposeful sampling are detailed in greater depth in the following chapter: Conduct of the study, Chapter 6.

The literature suggests that focus group participants must have the ability to express their experiences and feelings with ease, in the language in which the study is understood and implemented (Omery, 1983). Supporting this, Duffey (1985) suggests that it is important to identify a sample that is representative of a larger population of people and that the richness of the sample comes from gaining a variety of opinions that will support or refute the inquiry in question. Cormack (2000) adds to this, suggesting sample size is kept small in order to maintain a rich, diverse source of material. These points were contemplated when considering the purposive method of sampling for both phases of this study.

Within phenomenological studies the adequacy of sample is not a matter of size but also of ensuring that all aspects of the phenomenon are represented in the data collected (Morse, 1994). The guidelines for sample size are clear and relate to data

saturation. The general rule is when the same stories, themes, issues and topics are emerging from the study participant's data saturation has occurred and a sufficient sample size has been reached (Ritchie and Lewis, 2003). When no new themes were identified from the transcripts, from both phases of the study, this was taken as a sign that saturation of the data had occurred. This is detailed further in Chapter 6.

5.5 Method of data collection

Approaches to qualitative research tend to have certain requirements, limitations or preferences for methods of data collection (Strauss & Corbin, 1990, Holloway and Wheeler, 2010, Polit and Beck, 2013) and phenomenology is no exception. Methods of data collection should allow participants to offer 'a rich, detailed, first-person account of their experiences' (Smith et al, 2009, p56) and within the approach observation, in-depth interviews and focus groups are advocated (Holloway and Wheeler, 2010). To achieve the aim and objectives for this study a data collecting approach needed to explore patients' interpretations and nurses' perceptions. Therefore, unstructured interviews were undertaken in the first phase of this study and focus group discussions in the second.

5.5.1 Interviews

Data related to living with a stoma were generated through the use of in-depth interviews. Interviews are a method used to generate data about a phenomenon of interest (Pontin, 2000) and are frequently used in qualitative research designs, to elicit data regarding people's experiences and accounts of events, their opinions,

attitudes and perceptions as well as biographical and demographic details (Pontin, 2000). Smith and Osborn (2008) suggest the interview offers an appreciation that encompasses two aspects of interpretation; identification and make sense of. Interviews should therefore be participant-led, facilitated by an empathetic, enquiring interviewer.

The usual types of interview techniques are face-to-face, telephone, panel, group and sequential. The most commonly recognized interview methods are the structured, semi-structured, and unstructured interview. As the intention of phase one of this study was to encourage the patient participants to explore their experience in as full a way as possible, unstructured interviews were indicated (Pontin, 2000). This type of interview fits well with the phenomenological tradition of inquiry where the intent is to let the participant say in their own words what is relevant and pertinent to them and hence, to reveal the meanings they attach to their experiences and behaviour (Silverman, 2000). The unstructured interview is guided by a list of topics that need to be covered in the interview (See Table 6.2). This generally allows the interview to flow in a more conversational manner, the guide being used to only ensure that the topics for the interview remain the primary focus.

Unstructured interviews are often described as in-depth interviews (Streubert and Carpenter, 2010). This description is helpful in that it draws away from the notion that an interview steered by a topic guide cannot be truly unstructured (Holloway and Wheeler, 2010). The identified topics are covered in the order most suited to the

participant, to allow responses to be probed and explored and to permit the researcher to respond to relevant issues raised spontaneously by the participant. As the nature of the unstructured interview was seen to provide an opportunity for the participant's to speak freely, this became the method of choice.

It provided greater scope in the answers and responses (Streubert and Carpenter, 2010) thereby providing richly detailed data (Bryman, 2008). Participants were initially asked a nonthreatening open question of their experiences; 'How are you feeling today?' In accordance with the chosen method, minimal leads were then made (Parse et al, 1995) allowing participants to talk about the issues important to them. The process of data collection, in particular the interview topic guide is discussed further in Chapter 6; Conduct of the study.

5.5.2 Interview style

There are a number of different theoretical perspectives that relate to in-depth interviewing and different types of interview. However, the features that are broadly consistent are the flexible nature of the data collected and the fact they are captured in the natural form (Legard et al, 2003) to the participant. Whilst it is generally agreed that the in-depth interview is an appropriate method for generating data for qualitative research, the question arises as to whether there is a particular way to tailor an interview to reflect the particular type of research approach being used. Sorrell and Redmond (1995) suggest that an interview is shaped by a specific research methodology. As research methodologies arise from philosophical

traditions 'it is important to apply research processes in ways that are congruent with the study's philosophical foundation, thereby ensuring the research maintains its fidelity to a line of philosophical thought' (Geanellos, 1999, p40).

Few papers provide information relating to how a chosen philosophy guides the conduct of the research interview but from those available several differences were detected (Jasper, 1994, Holloway and Wheeler, 2010). Papers relating to interviews guided by four different philosophical traditions were found: the ethnographic interview, the phenomenological interview, the grounded theory interview and the hermeneutic interview (Sorrell and Redmond, 1995, Polit and Beck, 2013). Most focus on three particular areas: the purpose of the interview, the interviewer-interviewee relationship and the approach to the interview. Perhaps the most important of these areas in relation to the current study was the approach to the interview and it is here that particular differences are noted. These are discussed further in Chapter 6, related to the conduct of the study.

In phenomenological interviewing, where the interview was structured by the respondents' stories (Sorrell and Redmond, 1995, Holloway and Wheeler, 2010, Polit and Beck, 2013), the role of the researcher is facilitative rather than controlling, with the interview participated in equally by both interviewer and participant. The approach here is through the use of reflection, clarification, requests for examples and descriptions with the intention that the interview should be in-depth (Wimpenny and Gass, 2000) and reflective (Munhall and Oiler-Boyd, 1993).

The method of data collection within Phase two was focus groups. It is recognised that focus groups are group discussion that are conducted to review a particular subject and that they are useful in examining what people think, their views and beliefs about a topic (Kitzinger, 2005). The focus group is also an effective way of determining why different groups think of things in different ways. The study's objectives included a need to understand how specialist stoma care nurses address the adaptation needs of patients undergoing stoma surgery whilst exploring the complexities of transmitting information. Focus group discussion was seen as an appropriate forum to elicit such data.

5.5.3 Vignettes

Prior to the second phase of the study, vignettes were created from the patient narratives. Vignettes have a range of different purposes and meanings (Barter and Renold, 1999, Wilks, 2004) with the potential to assist in a deeper interpretative understanding of significances arising from data (Wareing, 2010b).

Employing vignettes can elicit perceptions, opinions, beliefs and attitudes from respondents (Barter and Renold, 1999, Sim and Wright, 2000, Wilks, 2004). Within an interpretative paradigm, vignettes can be used for tapping into general attitudes and beliefs or as a complementary approach alongside other data collection methods, to enhance or generate further data (Wareing, 2010a). The structure of the vignette is important, so not to lose the underlying issue to be addressed. In this instance the vignettes were created directly from the patients' narrative. The

process of creating the vignettes used for the focus group discussion is detailed in Chapter 6.

5.6 Analysis

In qualitative research, the process by which data analysis is undertaken is fundamental to determining the credibility of the findings (Streubert and Carpenter, 2010). Essentially, analysis allows the transformation of raw data into a final description, narrative, themes or categories (Streubert and Carpenter, 2010 Holloway and Wheeler, 2010, Polit and Beck, 2013). The analytical process was undertaken in three stages; Stage 1 - thematic analysis of phase 1; Stage 2 - thematic analysis of phase 2; Stage 3 - further analysis of phase 2 using the emotional intelligence theoretical framework by Mayer and Salovey (1997) as a conceptual framework (See Table 6.7).

Phase one of this study explored patients' common experiences as lived as a person with a newly formed stoma, a phenomenological approach. The purpose of data analysis in phenomenology is to "preserve the uniqueness of each lived experience of phenomenon, whilst permitting an understanding of the meaning of the phenomenon itself" (Jasper, 1994, p311). Parse et al (1995) supported this as they considered the process of analysis to be rigorous and systemic as it is intended to facilitate the identification of essences of phenomenon. In view of this, a thematic analysis was carried out at stage 1 of the analysis process.

Thematic analysis is referred to as a 'method for identifying, analysing and reporting patterns, in this case, themes, within the data (Braun and Clarke, 2006, p79). Smith (2007) describes thematic analysis as an iterative and inductive cycle which proceeds to draw upon the following; close line-by-line analysis of the claims, concerns and understandings of each participant, identification of emerging patterns, coding data, developing relationships with data; relative to context, organisation of data for purposes of audit trail, develop coherence and plausibility of interpretation and finally, personal reflection. The manner in which the thematic analysis took place is outlined in greater detail in Chapter 6; Conduct of the study.

Phase two of this study explored the complexities of transmitting specialist knowledge and skills by the stoma care nurse as they facilitated the patient's ability to adapt to stoma surgery. At stage 2 of the analytical process these findings were subjected to a thematic analysis. However, the analysis failed to highlight clearly the pedagogical components of specialist practice and a third stage to the analysis process was considered.

A theoretical framework of emotional intelligence (Mayer and Salovey, 1997) was chosen for the third stage of the analysis process. Unlike other emotional intelligence theoretical frameworks (Bar-On, 1997, Goleman, 1995) this considers ability alone rather than with personality. The focus of this study was to explore specialist nurses ability rather than personality and therefore deemed the more appropriate framework to use. The framework guided the analysis to identify the pedagogical components required to prepare nurses for specialist stoma care

practice. The conduct of both the thematic and analysis using a conceptual framework are detailed in Chapter 6.

5.7 The abilities model of emotional intelligence

Emotional intelligence is defined as the 'ability to recognize the meaning of emotions and their relationships and to use them as a basis of reasoning and problem-solving' (Mayer et al, 2001, p234). Mayer and Salovey (1997) believed that emotional intelligence is related to thinking, through the ability to use reasoning, by way of information, to find meaning. This model is composed of four branches. Each branch has specific characteristics to meet the criteria of emotional intelligence. Each level or branch builds upon the previous one and awareness of what each branch offers is individual. Enhancing relationships with others is a key component of healthy emotional interactions. The following is a brief description of the four branches. The first branch is the perception of emotion, which is the skill of accurately distinguishing emotion within oneself and others. Using emotion to facilitate thinking is the second branch. This branch enhances an individual's ability to assimilate emotion, to facilitate thinking and to prioritize thinking and judgements.

Understanding emotion follows as the third branch, which allows application of the emotional knowledge gained in the first two levels of skills to translate emotions to meaning within the context of events. The highest level of the skills of emotional intelligence is the conscious regulation and management of emotion. This level of the model allows the individual to remain receptive to emotional information while

reflecting on the usefulness of it. This reflective ability provides the ability to evaluate emotional reactions not only within self but also those conveyed by others.

5.8 Ethical implications

All research needs to observe the participants' rights of autonomous choice and informed consent, confidentiality and anonymity, respect and dignity without causing harm or exploitation (Streubert and Carpenter, 2010). This study considered the patients' confidentiality and anonymity as well as their potential vulnerability. Discussing sensitive issues such as body image, self-esteem, attractiveness, sexuality and fertility, or disclosure might have heightened potential psychological disturbances for the participants. These issues were considered and highlighted to the patient when seeking informed consent. Chapter 6 details these ethical considerations in greater depth.

5.9 Trustworthiness

To ensure trustworthiness in this qualitative study, the principles of rigour were applied. Rigour is a means of demonstrating the credibility and integrity of the research process (Koch, 1998, Burns and Grove, 2003). Selecting the most appropriate method for data collection for each of the phases of this study helped established its credibility as part of the audit trail.

Rigour within qualitative inquiry reflects the extent to which the data are a true likeness of participants understanding of the phenomenon under investigation

(Crotty, 1996). Purposeful sampling for both phases of the study enhanced the possibility of gaining valuable and rich information. Similarly, clarification of questions during the patient interviews at phase one enabled the interview to get close to the lived experience; clarification at the focus groups in phase two offered an understanding of the complexities of the specialist nurses role. This is illustrated by the representative narratives from the transcripts and presented in the findings (Chapter 7).

In both phases of this study, various strategies were used to ensure this was upheld with particular attention to procedural and ethical rigour. This referred to the keeping of a reflective journal. This allowed regular interpretative notes regarding thoughts and findings including judgements particularly regarding the methods chosen, assumptions and a personal reflection of the research process; both of which assisted the audit trail (See Table 5.3). The ability to reflect and be reflexive ensures the researcher is open and transparent to the decisions made during the research process (Koch, 1998, Epp, 2008, Engward and Davis, 2015) and therefore an important aspect of the trustworthiness within the qualitative research process. Reflection and reflexivity are outlined in greater depth within Chapter 9; Reflection.

5.10 Summary

This chapter has established the philosophical underpinnings and theoretical assumptions upon which both phases of this study have been built. It demonstrates the relationship between the research question and the methodology. It has

explored the research design, including the selection of the sample and sampling methods used to meet the aim and objectives. Consideration has been given to the methods selected for the data collection, ensuring quality and trustworthiness. The role and influence of the researcher in both data collection and analysis has been considered. How the study was conducted will now follow.

Table 5.3 – *The audit trail*

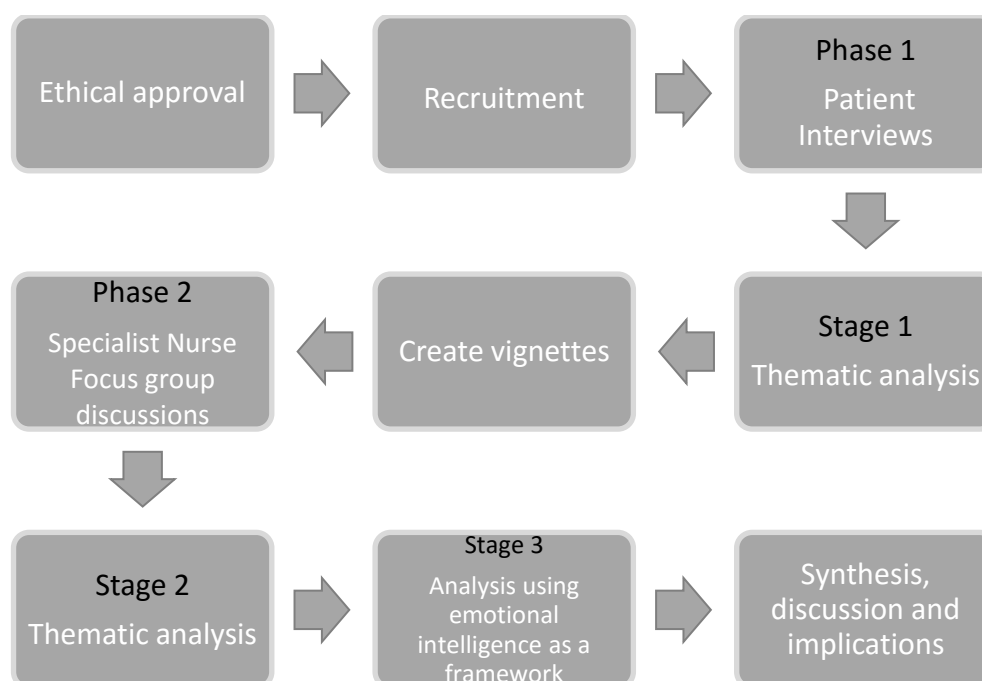
The audit trail
<ul style="list-style-type: none"> • In-depth and prolonged engagement with the data (Lincoln and Guba, 1985, Ashworth, 1997) • Exploring and making explicit bias and assumptions through reflexivity (Lincoln and Guba, 1985, Koch, 1998, Streubert and Carpenter, 2010) • Peer review of concepts and debriefing to enhance credibility (Lincoln and Guba, 1995, Robson, 2002) • Exemplifying concepts with verbatim quotes (Johnson, 1997) • Reframing the meanings with informant at the time of interview to ensure what was interpreted reflected the true meaning (van Manen, 1990) • Reflexivity (Cutcliffe, 2003)

6. Conduct of the study

6.1 Introduction

This study arose from an interest in how specialist nurses facilitate the needs of patients with newly formed stomas as they adapt to their new lifestyle and to develop a pedagogical perspective so to inform and develop educational progression for specialist nursing practice. The previous chapter outlined the philosophical assumptions and theoretical underpinnings of the methodology and methods used for both phases of this study, namely phenomenology and focus group methodology. This chapter will demonstrate the application of these principles, taking the reader through a chronological account of the phases to this study (See Figure. 6.1).

Figure 6.1 - Flow chart representing research process



6.2 Ethical considerations

Ethical considerations are important at all stages of the research process. In this study ethical issues to be considered included purpose of the research, obtaining permission to proceed and access participants, informed consent and issues of confidentiality and anonymity, data collection issues including data storage and the writing up of the thesis. Full ethical approval for the study was granted from the North West London Research Ethics committee (See Appendix 1). Minor amendments were required following the initial submission. These included clarification of terminology used and confirmation of safe guarding strategies (See Section 6.2.3). This was followed by local research and development (R&D) approval from North West London Hospitals NHS Trust, Harrow and Oxford Hospitals NHS Trust, Oxford (See Appendix 2): the two research sites. Ethical approvals from all three committees were approved by the end of the third year. A small grant of £1,850 was awarded from the Seed Corn Research Fund at North West London NHS Hospitals Trust. This covered administration costs, such as transcribing the focus group data and travel expenses.

6.2.1 Informed consent

Once the participants had agreed to take part in the study, informed consent was obtained. At both stages of the study consent was sought prior to commencing the interview or focus group. Participants were assured that taking part was entirely voluntary and particularly for the patient participants, non-participation would not reflect upon any care or treatment they were currently receiving. Consent included

an agreement for the interview or focus group discussion to be tape recorded. See Appendix 3 for copy of the patient and nurse participants consent forms.

6.2.2 Confidentiality and anonymity

Standards of confidentiality within qualitative research can be potentially compromised due to the rich description of individual narratives (Mays and Pope, 1995). Following the patient and focus group interviews, the tapes were uploaded onto a secure data storage system which was password protected, in preparation for the transcribing process. The interviews were then deleted from the digital tape recorder. Once transcribed the files were uploaded onto the same secure data storage system and kept for the duration of the analysis. All non-anonymised data was password protected and at no point was it accessible or heard by unauthorised persons or persons unrelated to the study. All potentially identifying material such as consent forms, were stored in a locked cabinet at the researchers home and destroyed, i.e. shredded, following completion of the study. Participant anonymity was upheld using codes as identification. Table 6.1 illustrates the patient participant coding whilst Table 6.4 illustrates the nurse participants coding. Participants were assured that the information obtained would be used only for the purpose of this study and any subsequent publications.

6.2.3 Potential vulnerability

All research needs sensitivity, caution and respect for the physical and emotional well-being of participants (Holloway and Wheeler, 2010). An ethical issue of concern

raised by the study was the potential vulnerability of the patient participants.

Patients were asked to share their experiences of having a newly formed stoma. This had the potential to evoke previously discarded thoughts and feelings, so these potential difficulties were discussed with a clinical psychologist, who also agreed to the offer of psychological support to those participants who felt distressed following the interview. Whilst no participants felt they needed this, it was important to be able to offer them additional support.

Following each interview, information regarding the patients GP was sought from the patient. A letter (See Appendix 4) was sent informing the GP of their patient's inclusion in the study. This included an outline of the nature and purpose of the study and a copy of the patient's reply slip and consent form.

6.3 Phase 1 – the patients experience

Phase 1 of the study explored the patient's experiences of living with a newly formed stoma. Participants were recruited by specialist stoma care nurses at the two research sites, using the selection criteria below.

6.3.1 Research sites

Phase one of this study was conducted within the context of two NHS Hospital Trusts, both renowned for being large tertiary referral centres specializing in colorectal and gastrointestinal surgery. The average referral rate for each site was 4 – 6 new stoma surgeries per month and therefore deemed a suitable clinical

environment to recruit. The researcher was known to both sites but was neither delivering direct clinical care nor directly managing any of the staff.

6.3.2 Selection criteria

Selection criteria were influenced by reviewing the aim of the study and deciding the lines of enquiry to be pursued (Ritchie and Lewis, 2003). Following a review of the literature it was decided to keep selection criteria to a minimum in order not to exclude patients unnecessarily. It was decided the following patients should be included;

- Be 18 years and over
- Have undergone formation of a colostomy or ileostomy
- Be a minimum of 3 months post stoma surgery
- Be able to speak English fluently
- Be physically and mentally willing to participate
- Be able to freely give written informed consent

As interviews were the chosen method of data collection for this phase of the study it was decided that all participants had to be able to freely express themselves in English. Although the funding for an interpreter was not taken into account, it was felt there might be some difficulties with translation which might result in the

trustworthiness of the data being compromised (Ritchie and Lewis, 2003) as there could be no assurances of the authenticity of the information translated.

6.3.3 Recruitment of sample

The sample size was influenced by the theoretical underpinning, the heterogeneity of the participants and the research inquiry (Gerson and Horowitz, 2002). The first eight participants recruited in the sample were chosen to reflect the processes being explored (Denzin and Lincoln, 2011). A good participant was considered to be someone who was 'information-rich' (Patton, 1990, p169) and willing to clearly communicate the experiences following surgery resulting in the formation of a stoma. They were therefore purposively sampled. Recruitment to the study was much slower than predicted as the researcher was reliant upon specialist stoma care nurses at each research site to give out patient information packs as part of the recruitment process. The specialist stoma care nurses at both sites were briefed by the researcher as to the nature of the study. This offered an opportunity to clarify all aspects of the study so that selection and recruitment was simple and straightforward. The nurses were asked to recruit patients in the post-operative phase ensuring stoma surgery had taken place. Unfortunately this did not occur on four occasions at one site requiring the researcher to reinforce the recruitment and sampling criteria for the study. Each research site was given an appropriate number of participant information packs (See Appendix 5).

Following a verbal explanation from the specialist stoma care nurse at each site, patients were given an information pack containing an outline of the study proposal, information regarding their participation and a reply slip with a self-addressed envelope. All participants were asked to return the reply slip, indicating their interest in the study or not. On receipt of the reply slip, if the participant indicated their wish to be included in the study they were contacted by the researcher to arrange a suitable date, time and venue for the interview to take place.

Table 6.1 – Patient participant demographics for Phase 1

Patient code	Male/ Female	Age	Research site	Diagnosis	Type of stoma	Date of surgery	Date of interview	Duration of interview (Hrs.mins)
PT#1	F	74	2	Ca Anus	Permanent colostomy	24.05.11	17.08.11	1.15
PT#2	M	24	1	Crohn's	Temporary ileostomy	10.07.11	18.10.11	0.48
PT#3	F	54	2	Crohn's	Temporary ileostomy	02.08.11	07.11.11	1.23
PT#4	F	66	1	Diverticular Disease	Temporary colostomy	20.08.11	15.11.11	1.21
PT#5	F	45	1	Severe constipation	Permanent colostomy	18.08.11	16.12.11	1.49
PT#6	M	61	1	Ca Bowel	Temporary ileostomy	07.09.11	24.11.11	1.04
PT#7	M	19	1	Familial Adenomatous Polyposis	Temporary ileostomy	09.08.11	28.11.11	1.29
PT#8	M	64	1	Ulcerative Colitis	Permanent ileostomy	28.09.11	12.12.11	1.09

A total of 40 participant information packs were distributed to the two research sites of which 24 were given to potential participants by the specialist stoma care nurses.

Ten participants' declined taking part in the study, whilst six were deemed unsuitable for the reason that no stoma had been formed (n=4), early stoma closure had taken place (n=1) and the participant was receiving adjuvant therapies and therefore changed their mind in taking part in the study (n=1). The purposive sampling strategy therefore recruited eight people with a variety of diagnoses and stoma types, illness histories and modes of presentation who had recently experienced stoma forming surgery as illustrated in Table 6.1.

6.4 Data collection

6.4.1 Interviews

Interviews were the chosen methods for data collection at phase one. They were carried out at the convenience of the participant and researcher, at a venue of the participant's choice. A semi-structured interview approach was used, with the aid of a topic guide (See Table 6.2). The topic guide ensured similar types of data were collected from all the participants and had been developed from the contextual information and literature review previously presented (See Chapters 2 and 3). The topic guide was peer reviewed prior to commencing the data collection. An hour was allocated for each interview. All but one exceeded this time (See Table 6.1) implying the participants felt comfortable and at ease during the interview to speak freely and honestly about their experience.

Once consent had been sought (See Appendix 3), the researcher ensured the participant was in a comfortable environment with no disturbances so the interview

could proceed. Aiming to ensure an empathetic style of interviewing, the researcher, made every effort not to lead the participant but to facilitate their descriptions of their thoughts and feelings.

Each interview was taped-recorded. Reflective notes were taken before, during and after the interview to describe interview technique, verbal and non-communications with the participant as well as the emotional effect on the researcher and added to the participant's interpretations as part of the interpretative process. This assisted with the reflection and reflexivity required of a qualitative approach (See Chapter 9). It was the researcher's choice to transcribe each tape recording, as this aided the familiarisation of data for analysis.

The researcher introduced herself as the principal researcher and did not disclose previous clinical expertise so not to bias the interview in any way. A total of eight interviews took place over a period of 4 months (August – December 2011) (See Table 6.1). The topic guide was constructed so that the initial question was asked in such a way as to encourage the participant to narrate freely when answering. The interviews commenced with a brief summary of the project's intentions and hence, the intention of the interview, which was sufficient to generate free conversations with the participants. In the topic guide (See Table 6.2), open-ended questions, relating to the study objectives, provided participants with the opportunity to fully explain their experience of the phenomenon of interest (Streubert and Carpenter, 2010).

A range of probes and other techniques were used in order to achieve depth of answer in terms of perception, exploration and explanation and follow-up questions were used to obtain deeper, fuller understanding of the participant's meaning. It was important to explore all the factors that underpinned the participant's answers including their reasons, feelings, opinions and beliefs. This, then, provided what Legard et al (2003), defines as explanatory evidence.

Table 6.2 - Interview topic guide for Phase 1

Interview time point	3-4 months post-operative
Interview content	<ol style="list-style-type: none"> 1. How are you feeling today? 2. Looking back, can you summarize what the last 3-4 months has been like for you? 3. What has promoted your recovery? 4. What has hindered your recovery? 5. What impact has the surgery had on you? 6. Are there any lasting effects? 7. What do you consider to be the key features of the entire experience? 8. Have you had any crises – what happened, what could have been different? 9. What activities, if any, have been harder to return to and why do you think this is? 10. Do you have any concerns for the future?

6.5 Thematic analysis

All the participants' data contributed to the process of analysis. The participants' collective experiences provided rich narratives which were inductively explored. Initially, the taped interviews were transcribed by the researcher followed by an exploratory thematic analysis where the data collected was carefully read and re-

read. Key words, themes, repetitions or links in the data were sought, that would help outline the analysis prior to the analysis taking place. Thematic analysis 'involves searching across the data set to find repeated patterns of meaning' (Braun and Clarke, 2006, p86). Initially the process of analysis was conducted using the software package, Nvivo 8. Unfortunately, the researcher found conceptualising data on the computer screen too difficult. As more and more tree nodes were created, segments of the text were removed from the whole, creating a loss of perspective. So the exploration of the data reverted to manual coding by using coloured highlighter pens on printed transcripts which proved more manageable.

During this process, the transcriptions were read and re-read as a means of familiarisation. This enabled the researcher to make sense of the individual transcriptions, whilst making links between all the participants. Throughout this process, themes were searched for. Seeking repetition of key words in the data, created a theme: repeated words or terms by four or more participants indicated a theme. Subsequently six recurring themes emerged. These themes illustrated the challenges patients faced in adapting to a newly formed stoma, illustrating how the participants felt able to come to terms with and begin to accept their new way of life. This was considered as the first stage of analysis (See Chapter 7, Figure 7.2).

6.5.1 Emerging themes

The thematic analysis offered a total of 6 emerging themes; seeking assurances, permanence versus reversibility of stoma, anticipated stigma, psychological

projection, worthwhile sacrifice and sense of achievement (See Table 6.3). These themes recognise an aspect of the adaptation of patients having undergone stoma surgery at 3 months post-surgery as interpreted by the researcher with verification from the patient's narratives. These themes are discussed in greater depth within Chapter 7; findings.

Table 6.3 - Emerging themes from Phase 1 with examples

No.	Theme	Example from patient narrative
1	Seeking assurances	<i>"I only agreed to have it (the surgery) done if the surgeon promised to make the stoma temporary" (PT#3, female, 54 years, Crohn's disease)</i>
2	Permanence versus reversibility of stoma	<i>"I'm only coping with it (the stoma) because I've got to How I might feel about it if it (the stoma) was there all the time, well that's a different matter" (PT#4, female, 66 years, Diverticular disease)</i>
3	Anticipated stigma	<i>"I'm the sort of person that would lie about how ill they actually are, I mean I'm not in denial but just don't admit to being ill" (PT#2, male, 24 years, Crohn's disease)</i>
4	Psychological projection	<i>"I just think if this has been my daughter, you know young, single girl, I don't know how she might have coped" ". (PT#6, male, 61 years, Ca. bowel)</i>
5	Worthwhile sacrifice	<i>"I think at the moment it's nice just to feel well, you know, it's been such a long time, so you know it's a worthwhile sacrifice". (PT#2, male, 24 years, Crohn's disease)</i>
6	Sense of achievement	<i>"I'm continuing to get better and able to enjoy a vast array of food has been a tremendous achievement" (PT#8, male, 64 years, Ulcerative colitis)</i>

6.6 Creating the vignettes

The emerging themes (See Table 6.3) characterized how patients adapted to stoma surgery. To ensure that no underlying issues were lost, these themes became the

starting point for the creation of vignettes with each theme offering a topic area for discussion at the focus groups in phase two of the study. The vignettes were created directly from the patient's narratives, not only to make sense of the experience but also to emphasise the vignette's authenticity.

Table 6.4 – Outline of vignettes

Themes from Phase 1	Outline of vignettes	FG No.
1. Seeking assurances	Vignette 1: Feelings of hatred towards stoma, totally ruined lifestyle Vignette 2: Poor stoma positioning even though sited appropriately Vignette 3: Promised QoL would improve following surgery	FG#1 FG#6
2. Permanence Vs reversibility of stoma	Vignette 1: Being caught in limbo Vignette 2: Permanent stoma, will cross that bridge when it comes. Vignette 3: Fears stoma will be permanent Vignette 4: Not wishing to live with a stoma for longer than is needed	FG#1 FG#3 FG#7
3. Anticipated stigma	Vignette 1: Only parents aware of stoma, avoids telling others Vignette 2: Concerned about others 'talking' Vignette 3: Denial of disease	FG#4 FG#7
4. Psychological projection	Vignette 1: Projects own fears and hatred of stoma onto relative Vignette 2: Projects fears and anxieties of rejection from pet dog rather than husband as this is easier to discuss/accept	FG#2 FG#5
5. Worthwhile sacrifice	Vignette 1: Re-evaluating life Vignette 2: So good to feel well again Vignette 3: Putting things into perspective Vignette 4: It's annoying but at least no fear of getting cancer	FG#4 FG#5 FG#6
6. Sense of achievement	Vignette 1: Exploring role reversal and how poignant this is Vignette 2: Since surgery able to eat anything and everything.	FG#2 FG#3

A decision then had to be made as to the number of vignettes within each theme so not to saturate the focus group discussion but at the same time provide enough information for the discussions to be meaningful. The vignettes had to be limited as it was not possible to include all the relevant categories of factors. It was decided to

offer up to 4 vignettes per theme as an illustration (See Table 6.4). The vignettes were formed as part of the focus group information pack presented to participants prior to commencing the focus group (See Appendix 6). Themes for discussion were chosen at random by the focus group facilitator and were presented on paper as well as read aloud by the facilitator.

6.7 Phase 2 – transmission of knowledge and skills by the specialist stoma care nurse

The translation of knowledge and skills of the specialist stoma care nurse were explored with a particular emphasis towards the adaptation of the patient following stoma surgery. Focus groups were chosen as the ideal method of data collection because it created a forum to where thoughts, feelings, attitudes and ideas could be shared with the sole purpose of eliciting how specialist nurses would address patient issues as characterized within the vignettes developed from the narrative of participants from Phase 1.

This section explores the sequence taken to demonstrate how careful preparation, implementation of the stages before, during and after, was key to produce quality data to inform the development of an educational programme. The programme was designed to equip specialist stoma care nurses with the necessary skills to care for this patient group effectively, ultimately improving patient outcomes (Harvey-Jordan and Long, 2002, Redmond and Curtis, 2009).

6.7.1 Selection criteria

As with the patient recruitment, it was also important to recruit nurse specialists by reviewing the aim of the study and deciding the lines of enquiry to be pursued (Ritchie and Lewis, 2003). As the nurse specialists were to examine the selected vignettes representing the patient's experiences, it was imperative that the nurse worked as a specialist stoma nurse specialist.

6.7.2 Recruitment

Specialist stoma care nurses were initially recruited from their annual national conference for stoma care nursing (Association of Stoma Care Nurses UK). A flyer was created and placed within the delegate pack, inviting the nurses to participate in a focus group. The flyer outlined the study aim and objectives, offering the researcher's contact details as a point of contact should they wish to become involved. A total of 420 delegates attended the 2011 conference and 9 specialist stoma care nurses responded with an interest to take part in the focus group. This was a disappointing response and the recruitment strategy required further thought and discussion.

As part of a separate project, the researcher had been invited to facilitate a number of road shows regarding psychosexual issues and the patient with a stoma by an Ostomy Appliance and Supply Company. The road shows moved around the country and offered an ideal opportunity to recruit from a purposeful sample. Fortunately, the company financially supporting the road shows agreed to time table 1 hour into

the programme in order for the focus groups to take place (See Table 6.5). Prior to the start of the each roadshow, the researcher introduced the study and invited the delegates to participate. A total of seven focus groups took place during a period of five months.

The researcher was aware of being in the privileged position of having a captive audience from which to recruit. She understood the importance of ensuring the nurses were briefed, prior to the focus group and signed a consent form (See Appendix 3) confirming their understanding and acknowledging that they agreed to what was required of them. Throughout all seven focus groups, all themes were explored at least twice. The seventh focus group proved very difficult to arrange as annual leave and sickness prevailed; hence the four month break between FG#6 and FG#7 (See Table 6.5).

6.7.3 Nature of nurse participants

A total of thirty-nine specialist stoma care nurses took part in the focus groups. All of the participants met the criteria of a nurse specialist in stoma care as defined in Chapter 2. Their clinical experience relating to stoma care and/or gastrointestinal and colorectal nursing varied from three months to 23 years. This reflected a group of specialist nurses with a comprehensive array of knowledge and skills as well as diverse experiences both personally and professionally.

Table 6.5 – Nurse participant and focus group demographics for Phase 2

Focus group code (Nurse participant code)	Location	No. participants per focus group	Discussed vignettes (1-6)	Date of focus group	Focus group time(hrs/ mins)
FG#1 (NP1-6)	Newcastle	6	1 & 2	26 th June 2012	0.59
FG#2 (NP7-12)	Manchester	6	4 & 6	5 th July 2012	1.00
FG#3 (NP13-17)	Manchester	5	6 & 2	5 th July 2012	1.00
FG#4 (NP18-24)	Oxford	7	3 & 5	10 th July 2012	1.04
FG#5 (NP25-27)	Sheffield	3	5 & 4	17 th July 2012	0.56
FG#6 (NP28-34)	Cardiff	7	1 & 5	19 th July 2012	1.00
FG#7 (NP35-39)	Guildford	5	3 & 2	21 st November 2012	1.01

6.8 Focus group process

Each focus group took place in a hotel meeting room and participants were asked to turn mobile phones to silent or off. Each room was conducive to an environment where there would be no interruptions and the participants could concentrate on exploring the vignettes. Prior to commencing the focus group discussions ‘ground rules’ for each group, regarding confidentiality, were set. All focus groups took place after the road show. There was concern that this would result in the trigger of information recall as participants had explored similar issues within the road show consequently not necessary ensuring raw data. Due to nature of the road show it was not practical for the focus groups to take place before the road show started. In order to ensure continuity, the researcher took the decision to ensure every focus group ran after the road show.

The focus groups offered a way to make sense of an individual's experience of colorectal surgery and stoma formation, through the vignettes. The discussions allowed the voices of the participants to be heard, offering a personal and professional perspective to the vignette. The vignettes resonated with the participants own clinical practice. Familiar scenarios offered an apparent ease of conversation allowing open and free dialogue and where further explanation was needed, participants gladly brought examples from their own clinical practice to the focus group.

Discussions regarding the themed vignettes flowed easily between the participants. The facilitator ensured each participant contributed to the discussion. The participants demonstrated their respect for each other, by allowing each other to speak in turn. Where they did talk over each other, the facilitator was able to bring the conversation back to the main group and each participant in turn voiced their thoughts and experiences.

The vignettes triggered wide and varied discussions amongst the participants in the focus groups. Six out of the 7 focus groups brought scenarios from their own practice to the discussion in order to illustrate and clarify meaning to their dialogue. Some reflected upon clinical scenarios whilst others reflected organizational issues.

For the ease of transcription and analysis, each participant was asked to declare their name. The researcher then requested these names to be omitted from the transcribed script in order to maintain anonymity. However each nurse participant

was coded for ease of recognition during the writing up of the findings (See Table 6.5)

6.8.1 Choosing a facilitator

One of the key roles within a focus group is the facilitator. The facilitator has a significant influence on the collection of rich and valid information (Webb and Kevern, 2001) as they steer the group through the topic under discussion, in this instance the themed vignettes. This role was pivotal to eliciting responses relevant to the aim of the study (Happell, 2007). For this reason, it was essential to enlist a facilitator with an established reputation for communication and facilitation skills, with the purpose of encouraging the participants to engage actively in the discussion of the topic (Fern, 2001). Ensuring continuity, the same facilitator was employed for each focus group. The chosen facilitator was known to have suitable facilitation skills to assist the groups through appropriate discussion, as each theme was surveyed. It was imperative that the facilitator had adequate knowledge of this study and therefore an initial briefing took place prior to conducting any focus groups. Subsequent briefing took place in between focus groups where reflection and evaluation of the process of the focus group took place, ensuring continuity.

6.8.2 Facilitator briefing

The facilitator was briefed outlining the nature and purpose of the study. This briefing was supported by the research pack with copies of the research protocol and the six themed vignettes created from the participants within phase 1 of the

study. An outline of the schedule was also presented (see Table 6.6). This offered the facilitator adequate preparation.

6.8.3 Role of the observer

A journal was kept by the researcher, as an observer, for the purpose of note-taking. This ensured any background information was detailed and was used as additional information as seen within the analysis. Notes included demographics of the group, comments on the environment and flow of discussion, including noting any conflicts and common experiences that might have influenced the outcome of the study. These notes also assisted with the reflection and reflexivity required of a qualitative approach (See Chapter 9).

Table 6.6 – *Focus group schedule*

Focus group schedule
<ol style="list-style-type: none">1. Welcome/introductions including role explanation (facilitator/observer). Hand out focus group packs.2. Outline how discussion will progress, include confidentiality and sign consent forms. Establish ground rules.3. Sign post participants to written vignettes and read aloud assigned vignette4. Propose thinking time of 5 minutes5. Commence facilitation of open discussion6. Allow free dialogue related to vignette7. Clarify and summarize ensuring progression of dialogue8. Ensure discussions are kept to time9. Bring focus group to a close just before or just after 60 minutes

Participants sat at a round or oblong table for the duration of the focus group. This was of note as it offered the delegates good eye contact with one another, and possibly promote fruitful group discussions. The digital tape recorder being placed centrally ensuring all discussions could be clearly heard and recorded.

6.9 Thematic analysis

Using a thematic analysis approach, (Braun and Clarke, 2006) the transcripts from the seven focus groups were, in turn, read and re-read, in order to gain an insight into the individual focus groups as well as an overview sense of what was being said. This was considered to be the second stage of analysis (See Chapter 7, Figure 7.4). Grasping dialogue between the many participants within the focus groups required further reading, allowing for engagement with the data collected whilst also making an effort to identify meanings, in relation to the aim of the study. During this process, it was noted that some of the text was sometimes taken out of context and led to misplaced interpretation. Therefore, whilst reading the transcripts they were listened to simultaneously, using the original tapes. This offered a deeper understanding and enriched the analysis of the data collected; listening to the narratives whilst reading helped determine the authenticity of the participant's interpretation of the vignettes.

As with the analysis in phase 1, key words and repeated terms were sought in order to create a theme. If a key word or term was discussed in four or more of the focus groups, this then created a theme. The initial findings following the thematic analysis revealed five themes; skilled know-how, understanding self, hurdles to

accommodate, communication skills and uncertain ground. The themes were characterised by the role and responsibilities of the specialist nurse. These findings are however comparable to current literature (Waterhouse and Metcalfe 1991, Booth et al, 1996, Sirota, 2006, Simmons et al, 2007, Kotronoulas et al, 2009, Hoekstra et al 2012, Dyer and das Nair, 2012, Danielsen et al, 2013a) where insufficient awareness into the educational components of specialist practice is offered. The overarching aim of this study was to identify the transmission of knowledge and skills of specialist nursing practice so to inform educational curricula. In order to achieve this, further examination of the phase two data was required through a different lens prompting a third stage (See Chapter 7, Figure 7.6) to the analytical process.

Within the contextual information (See Chapter 2), reference was made to the personal attributes of specialist nursing practice as a contribution to ability and clinical skill. Recently there has been an increased awareness that cognitive ability and critical skills do not adequately account for academic and professional success (DH, 2010, RCN, 2010a). Literature has also explored the part played by emotional intelligence as a component of both academic and professional success (Akerjordet and Severinsson, 2004, Freshwater and Stickley, 2004, McQueen, 2004, Downey et al, 2006, Kooker et al, 2007, Hurley and Rankin, 2008, Banning and Gumley, 2010, Davies et al, 2010, James et al, 2010, Bailey et al, 2011, Codier et al, 2011, Por et al, 2011, Chaffey et al, 2012, Hurley, 2012, McConnell and Eva, 2012, Rankin, 2013).

Evidence clearly links emotional intelligence to developing close nurse patient relationships (Cobb and Mayer, 2000, McQueen, 2004) and understanding patient needs (Akerjordet and Severinsson, 2004). The emphasis on awareness of one's own emotions and those of others might be offered as an explanation for why some specialist nurses appear to be better at delivering patient-centred care than others. A decision was therefore made to utilise an emotional intelligence theoretical framework to act as a guide for a further stage of analysis. It was hoped to provide evidence to reflect the competency and skill needed of the specialist practitioner so to inform education. By undertaking a further analysis, it was assumed that further exploration of the narratives from the focus groups would provide insights into how nurses use their expert knowledge and experience, intuition and insight, in order to make sense of a clinical patient situation.

6.10 Analysis using a theoretical framework of Emotional Intelligence

The theoretical framework used for the third stage of analysis was the Emotional Intelligence framework of Mayer and Salovey (1997) (See Table 6.7). Unlike other emotional intelligence theoretical frameworks (Bar-On, 1997, Goleman, 1995) this considers ability alone rather than with personality.

The framework was used as a tool for analysis and therefore did not warrant use in its entirety. Mayer et al (2002) designed an instrument to measure emotional intelligent ability known as the MSCEIT tool. This did not form part of the data collection in phase 2 of the study. Therefore the branches and characteristics of the

framework where used solely for this third stage analysis. Each of the four branches has multiple characteristics (See Table 6.7). Words, expressions, phrases and conversations from the focus group narratives deemed to correspond to the branches and characteristics of the chosen emotional intelligence theoretical framework were identified and grouped together, revealing five essential elements to specialist nursing practice; the influence of emotions on critical thinking and decision-making, the use of empathetic and intuitive skills in clinical judgements, the ability to balance true self alongside professional self, the need to foster cognitive activity, good communication and creativity and preserving a conscious awareness of self to develop personal growth. In turn, indicating further comprehension as to the educational needs of specialist practitioners.

Table 6.7 - *Branches and characteristics of Emotional Intelligence theoretical framework (Mayer and Salovey, 1997)*

Branch 1	Branch 2	Branch 3	Branch 4
Perceiving emotions (PE) Characteristics <ul style="list-style-type: none"> • Self-awareness • Emotional self-awareness • Accurate self-assessment • Self-confidence • Gauging the mood • Tuning into your sense 	Facilitating thought with emotions (FE) Characteristics <ul style="list-style-type: none"> • Emotional self-control • Cognitive process – comprehension of language, learning, reasoning, problem-solving, decision-making • Intuition • Initiative • Adaptability • Conscientiousness • Trustworthiness 	Understanding emotions (UE) Characteristics <ul style="list-style-type: none"> • Empathy • Recognition • Clinical reasoning • Critical thinking • Clinical judgment 	Managing emotions (ME) Characteristics <ul style="list-style-type: none"> • Communication • Working as a team – working towards similar goals • Nurturing relationships – building rapport • Change agent • Leadership • Developing self and others – personal growth • Influences • Conflicts

As part of this third stage analysis, the transcriptions from each focus group were re-read and examined through this alternative lens. The narratives were then colour-coded representing the differing branches of the emotional intelligence theoretical framework. Following the analysis essential elements were identified; the influence of emotions on critical thinking and decision-making, the use of empathetic and intuitive skills in clinical judgements, the ability to balance true self alongside professional self, the need to foster cognitive activity, good communication and creativity and preserving a conscious awareness of self so to develop personal growth. Discussion of these essential elements and their implications to specialist practice is offered in Chapter 8.

6.11 Summary

A qualitative approach was chosen to fulfil the aim and objectives of this study. Phase one took a phenomenological approach and phase two a focus group methodology approach. Eight patients participated in phase one and offered insight onto the experience of living with a stoma as they adapted to the new lifestyle. With the aid of vignettes, phase two allowed the exploration of knowledge translation and skills among thirty-nine specialist stoma care nurses as they facilitate patient's adaptation, through seven focus group forums. This chapter has described the conduct of the study and some of the decision making process along the way. Further detailed reflexivity is presented in Chapter 9. The findings of this study are presented in the following chapter.

7. Analysis and Findings

7.1 Introduction

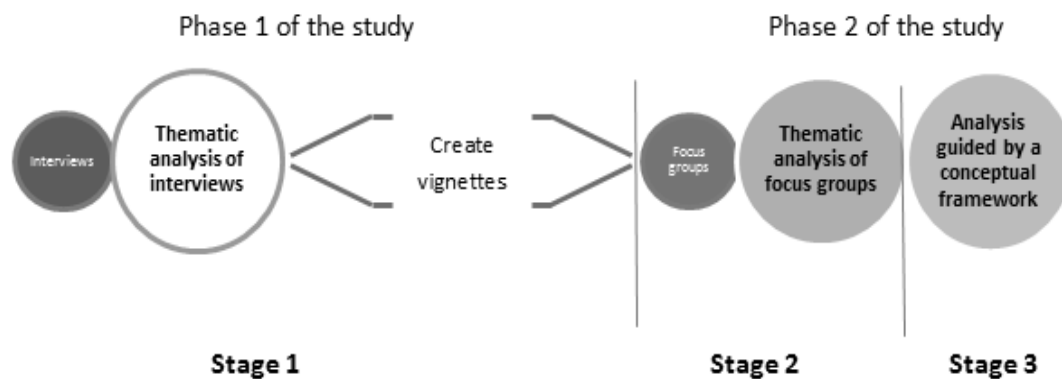
A qualitative approach underpinned this two-phase study. Phase one took an interpretative phenomenological approach and phase two, a focus group methodology. Eight patients participated in phase one, sharing experiences of an aspect of their adaptive journey towards living with a stoma. Vignettes were created from their narratives and used to stimulate discussion by the nurse participants in the focus groups of phase two. Thirty-nine specialist stoma care nurses took part in one of a series of seven focus groups. The analysis was undertaken in three stages across both phases (See Figure 7.1). This chapter demonstrates the analytical approach to each stage. In presenting the findings from both phases of the study a pedagogical perspective of specialist nursing practice in stoma care is articulated. Participant narratives from both phases have been chosen for inclusion as they best illustrate the thematic findings and essential elements to specialist practice. Presented in italics, the narratives are coded to maintain the anonymity of each participant.

7.2 Stages of the analytical process

The analysis was undertaken in three stages; Stage 1 - thematic analysis of phase 1; Stage 2 - thematic analysis of phase 2; Stage 3 - further analysis of phase 2 using the emotional intelligence framework by Mayer and Salovey (1997) as a theoretical framework (See Figure 7.1). Following the transcription of the interviews from phase

one, a thematic analysis was undertaken (Stage 1) and six themes emerged. These themes illustrated the challenges patients faced in adapting to a newly formed stoma. Each theme informed the development of the vignettes; eighteen in total (See Table 7.2). The vignettes acted as triggers to stimulate discussion amongst those who took part in the focus groups; data collected at phase 2. These data were analysed thematically (Stage 2) and five themes emerged.

Figure 7.1 - The three stages of analysis



These five themes were comparable to those of other studies, revealing a positive relationship between education and practice whilst advocating the need to improve education (Waterhouse and Metcalfe 1991, Booth et al, 1996, Sirota, 2006, Simmons et al, 2007, Kotronoulas et al, 2009, Hoekstra et al 2012, Dyer and das Nair, 2012, Danielsen et al, 2013a). However, these studies offer little insight into the educational components of specialist practice and as such are unable to inform the content and structure of educational delivery. The overall aim for this study was to identify the pedagogical perspective of specialist nursing practice to inform

educational curricula. For this to be achieved, further examination of the phase two data was required through an alternative lens; stage 3 of the analytical process.

As indicated in Chapter 2, there is a perception that nurse specialists are not only appraised on their clinical knowledge and skills but increasingly on how they manage their thoughts and emotions; emotional intelligence (Codier, 2012, Bingle and Davidson, 2014). Having a feeling for and understanding patient needs are essential skills for specialist nurses to empower patients towards self-efficacy (Simmons et al, 2007). Examining the data through the lens of an emotional intelligence theoretical framework was deemed appropriate. Reflecting the aim and objectives of this study, the ability (Mayer and Salovey, 1997) rather than personality (Bar-On, 1997, Goleman, 1998) theoretical framework for emotional intelligence was chosen. This model was used as a conceptual framework to guide the third stage of the analysis process (See Table 6.7).

Undertaking the third stage of analysis provided insights into how nurses use their expert knowledge and experience, intuition and insight, in order to make sense of a clinical patient situation, in turn providing evidence to reflect the competency and skill needed of the specialist practitioner, consequently to inform education.

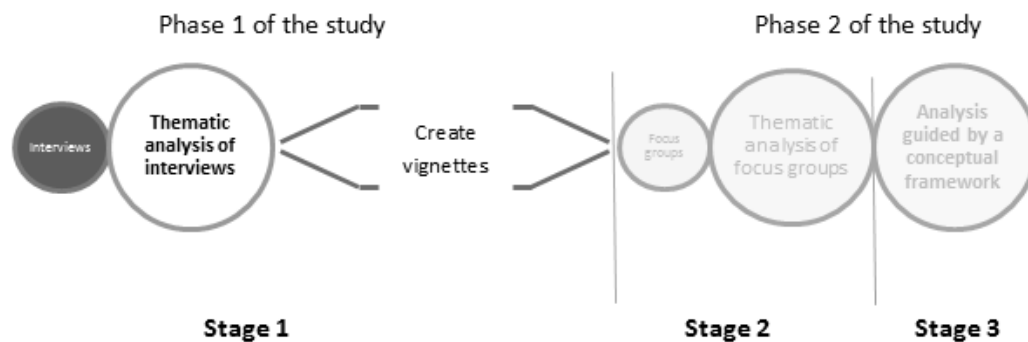
During stage 3 of the analysis, the focus group narratives were colour-coded to represent the differing branches of Mayer and Salovey's (1997) emotional intelligence theoretical framework. Examples of the characteristics of each branch were then highlighted and used as examples from the narratives.

Examples from the transcriptions are offered in italics, highlighting in which focus group the narrative arose and/or the theme and the relevant vignette. Each is coded to uphold the anonymity of the participants (See Tables 6.1 and 6.4). Where a short extract from the focus group discussion is presented the codes F (Facilitator), NP (Nurse Participant) and a participant number are used. The term participant alternates between patient/participant in phase one and nurse/participant in phase two.

7.3 Analysis and Findings from Phase 1

Purposeful sampling led to the recruitment of eight patients willing and able to participate in phase one of the study (See Table 6.1). The eight patient participants (4 men and 4 women) varied in age (19 – 74 years) and were interviewed once, over a time period of four months (August to December 2011). The time following surgery varied between 11-16 weeks (mean 13 weeks). Five of the participants were married, 2 single and 1 widowed. The diagnoses were colorectal cancer (n=2), Crohn's disease (n=2), ulcerative colitis (n=1), familial adenomatous polyposis (n=1), severe constipation (n=1) and diverticular disease (n=1). In three of the cases a permanent stoma was planned. Participant #4 had undergone emergency stoma surgery and had therefore received no pre-operative information from a specialist stoma care nurse. Following transcription of the patient participant interviews, stage 1 of the analysis took place and vignettes were developed (See Figure 7.2).

Figure 7.2 - Stage 1 of the analysis



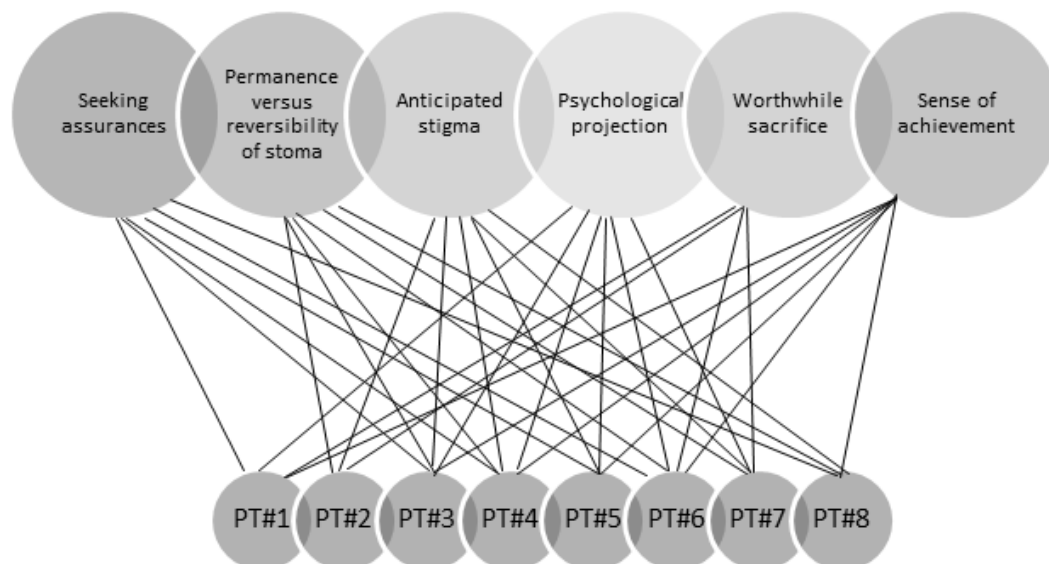
Thematic analysis resulted in six themes; seeking assurances, permanence versus reversibility of stoma, anticipated stigma, psychological projection, worthwhile sacrifice and sense of achievement. An example of how the analysis was undertaken is shown in Table 7.1.

Table 7.1 - Example of analysis; theme ‘Psychological projection’

Patient participant narrative	Narrative interpretation	Meaning	Theme
<p><i>“Years ago I had a job as a cleaner and met this lad who had a bag. I just thought crikey how young he was, cos at that time I didn’t know you could do things like that. He told me, not that he ever showed me, cos that would have been bad, but he told me a bit about the bag and everything. He told me that he’d had a girlfriend and she seemed OK with it and that’s a big thing, you think about, you know, your wife and your family, their disgust. I mean I just think if this happened to my daughter, you know pretty, young, single girl, I don’t know she might have coped but I guess we would have been there for her like they are for me”. (PT#6, male, 61 years, Ca. bowel)</i></p>	<p>Patient is recalling past experiences and imagining how unpleasant this experience might be for his daughter. Reflecting on his own fears and disgust for the stoma he projects these thoughts and considers how his daughter might have coped.</p>	<p>Feelings of disgust</p> <p>Displaced negative emotions</p> <p>Suppressed thoughts</p>	<p>Psychological projection</p>

The data revealed the personal challenges faced by the participants as they shared an element of their journey towards adapting to a new stoma. These challenges act as learning points for the development of the specialist stoma care nurse. The findings at stage 1 of the analysis are presented with an appreciation of the process of adaptation, as presented in Chapter 2, drawing attention to the challenges faced by the patients (See Figure 7.3).

Figure 7.3 - Mapped themes to the patient interviews



7.3.1 Seeking assurances

Seeking assurances was a view shared among the patient participants and centred on a number of areas. First, the realisation of a physical change in body image was immediate with the presence of the stoma with all the participants. Descriptions relating to the stoma such as *'it's gross'* (PT#3), *'ghastly'* (PT#4), or *'it (stoma) looked terrible'* (PT#5) and *'it's (stoma) offensive'* (PT#6) captured how the reality of having

a stoma felt for them. These terms implied the presence of the stoma was unlike anything they had anticipated and reflected that the change to body image was undesirable. Their narratives indicate an acute awareness of themselves and feelings of abnormality:

“It all just feels unnatural to me, I know I’m nowhere near perfect, it’s so visual as well, you know, it just doesn’t feel right, it’s not normal”. (PT#6, male, 61 years, Ca. bowel)

“I didn’t think I’d feel like this, you know, different, I just look and feel different. I’m always aware that it’s (stoma) there cos I feel my tummy to check it’s OK, check if it (stoma) needs changing. It’s just on my mind all of the time”. (PT#4, female, 66 years, Diverticular disease)

“When you first look it’s worse than you can ever imagine, it (stoma) looks slimy and swollen, the bags are bulky and it (stoma) smells; it’s gross” (PT#3, female, 54 years, Crohn’s disease)

These comments also reflect that these undesirable feelings were not only undesirable to them but likely to be appraised by others as undesirable too. Such feelings were seen to intensify should they experience common problems such as leaking stoma appliance, odour and noisy flatus, all sources of anxiety for which assurance was sought from the specialist stoma care nurses.

The findings revealed how distressing the participants perceived the entire experience of undergoing stoma surgery to be, as typified by the statement below:

“It’s all been a very traumatic experience, when I had the stoma at first, actually I think I was in shock, I felt numb. I remember seeing it (stoma) for the first time. I caught a glimpse of it in the mirror when I was in the bathroom. Ugh, I thought, that’s ghastly. I didn’t think it would look like that.

The nurse said 'it was a nice one (stoma)', neat I think she said, so I was slightly reassured". (PT#4, female, 66 years, Diverticular disease)

Describing the entire experience as *'traumatic'* illustrates the level of distress faced by several of the participants in coming to terms with their changed situation. Not wishing to look directly at the stoma this participant *'catches a glimpse'* of the newly formed stoma and is seemingly shocked by what she sees; a common reaction described by others.

Within the above narrative the nurse offers some reassurance, using the terms *'it was a nice one (stoma)'* or that it looked *'neat'*. This could be interpreted as an offer of some hope and encouragement to the patients, towards their recovery; a feature of the nurse specialists' role presented in Chapter 2.

Confirmation that recovery was as expected seemed important to the participants. For some, once the practicalities of caring for the stoma had been mastered, this led to the confidence to seek further assurances as to how the stoma might affect their lifestyle, work and social activities:

"The stoma nurse was brilliant in showing me how to look after the stoma and once I'd got the gist, I felt more confident to ask how life might be with it (stoma). We all have concerns but I was reassured when she told me how other people adapt, you know, that people do manage and do, do all the things that I did before my surgery, you know, going swimming, living a normal life with it (stoma), it wasn't going to stop me." (PT#5, female, 45 years, severe constipation)

Knowing that others coped with and adapted to life with a stoma offered hope and encouragement of adaptation for the participants. Alleviating the uncertainty surrounding or consequences of a stoma appeared to offer participants the ability to regain some normality in a situation they regarded as abnormal, as the following extract highlights:

"It was the embarrassment of knowing that and the sheer discomfort, physical discomfort of knowing that some point during the evening I would have to be rushing to the loo. It was getting worse and the frequency was, I had no control, I mean I would have to go 3 times in half an hour and potentially still have an accident. You can't do that in company and it was getting to the point where going out in the evening to anything was getting a little more unlikely. Now, well, now I've got the stoma, you could say I'm back in control." (PT#8, male, 64 years, Ulcerative colitis)

Seeking such assurances appeared to facilitate adjustment to a newly formed stoma, suggesting participants were planning ahead and beginning their process of adapting to their new stoma. The need for certainty increased their confidence and as one milestone was achieved after another the process of adaptation began to take place, as shown by the following narratives:

"Because of previous problems with eating, I asked what I could and could not eat and got the reassurance that I could eat pretty much anything". (PT#8, male, 64 years, Ulcerative colitis)

"It's reassuring to be told, with a bit of planning, I'll be able to travel abroad in the future". (PT#5, female, 45 years, severe constipation)

"I was really anxious about coming home and meeting people here (sheltered accommodation) again but the stoma nurse, she was very kind, and we talked through the worst thing that could happen. She said my concerns were quite normal which was good to know". (PT#4, female, 66 years, Diverticular disease)

Having described feelings of abnormality there was a shared need to know that their experiences and how they were feeling were 'normal' and the reassurances received from specialist nurses appeared to help with this.

All the participants emphasised that maintaining a degree of self-efficacy was important to them. This commonly involved adapting to the uncertain and unpredictable nature of living with a stoma. Describing the development of their own strategies for coping was perceived as learning from the experiences of others, seeking assurances from family and friends or by learning from their own experience through trial and error, for example:

"We have a neighbour who also has a colostomy. She says she can sometimes eat spicy foods and all the wrong kinds of vegetables." (PT#6, male, 61 years, Ca. bowel)

"I've asked friends who know me and I've said to them, 'can you see that (stoma appliance) blowing up' and they say well, yes, but we know it's you and it's you, it's part of you." (PT#4, female, 66 years, Diverticular disease)

"Because I've had this (stoma) before, I've actually taught myself really. It's trial and error." (PT#3, female, 54 years, Crohn's disease)

"I have a friend, she lives a long, long away, she's got one of these (stoma) and she wrote me a lovely letter cos she couldn't taste, neither. She told me how she coped with eating and everything." (PT#1, female, 74 years, Ca. Anus)

"Experience has taught me, to go to bed quite late. This is later than I might otherwise have done, it's so I don't sleep so long. I have to get up, you know, if I don't get to bed until nearer midnight there's a fair chance that if I wake up at 7 or half past 6 or something then I can cope with that. I think I still worry about leakage at night." (PT#8, male, 64 years, Ulcerative colitis)

These accounts suggest that practical and psychological strategies were harnessed; with some using their own initiative to address the uncertainties. Interpretation of advice from healthcare professionals varied and some participants acknowledged that they used their own judgement regarding the practicalities of stoma care.

Sources of reassurance appeared to assist recovery for some of the participants. For some, however assurance was sought through perceived promises. These promises were reported to have been made during pre-operative consultations with various healthcare professionals. They appeared to offer hope for the future. It should be noted; however, this sense of hope may have been based on inaccurate interpretation of the consultations and therefore is in danger of being considered false hope leading to a lack of coping and adjustment.

Participant #3 captures this, implying her self-efficacy had been compromised, she entrusted the decision making of the surgeon and agreed to undergo stoma surgery based on a promise:

“this is such a horrendous experience and I fully understand that for some people it changes their lives for the better and they can cope with it and everything it entails and maybe even their lifestyles can incorporate it much easier but I know for myself that it just doesn’t work, I don’t think it’s solved the problem, in fact it has created more problems, I just feel it has ruined my life, my whole life, my business, everything. I only agreed to have it (the stoma) done if the surgeon promised to make the stoma temporary”. (PT#3, female, 54 years, Crohn’s disease)

In this instance, the precise nature of the promise is not known. However, the participant was clear that she had been promised the reversal of her stoma and that

this expectation had facilitated her ability to cope and manage a situation which she described as being a *'horrendous experience'*. This example illustrates the challenges of interpreting and grasping the information provided by healthcare professionals prior to and following stoma surgery. These findings indicate that it was not so much the information provided that was important but rather the preparation for surgery including articulating fears and concerns.

A view shared by most of the participants was that developing hope would facilitate and expedite their recovery. This strategy seemingly enabled them to acquire confidence and to begin to re-establish independence; signalling progression towards adaptation. Maintaining this sense of hope to adapt was affected by whether the participants' expectations matched the reality of their situation. One participant commented how, although the decision-making process for surgery was justified, the realities of his expected outcomes were somewhat different, as shown:

"I've had my pouch for 20 years or so and it did me pretty well. Over the past 5 years things have begun to deteriorate so I was going to the loo more frequently and I was getting increasing pains in the stomach and the pouch. I was having to get up at night cos of the anal discharge and going out for meals became impossible. It just got worse and worse, until I was almost house bound. I spoke in detail to my surgeon and after some thought decided to have the pouch removed because she promised my symptoms would stop and my quality of life would improve don't get me wrong I am much better but I've still got the wretched discharge." (PT#8, male, 64 years, Ulcerative colitis)

For others, anxieties remained and, at times, were displayed as resentment towards the healthcare professionals especially when reality did not meet their expectations.

The following extract from participant #5's experience draws attention to this:

“The stoma wasn’t placed where we (stoma nurse and patient) agreed. At the pre-assessment the stoma nurse marked 2 points on my tummy, checking for creases, belt lines and all that and they get you to stand up and sit down to make sure it’s (the stoma) is in a good position and all this happened before surgery and then after, it was right in a crease. She (stoma nurse) even took photos and spoke to the surgeon, cos I had lots of creases from previous surgery. Now I know she didn’t promise where it (the stoma) would be placed but you’d think having gone to all that bother it would at least not be in a crease.” (PT#5, female, 45 years, severe constipation)

Other aspects of hope were identified within the findings (PT#1, PT#3, and PT #6) suggesting this facilitated progression towards adaptation to life with a stoma. Having hope rather than false hope early on in the post-operative period was evident as being helpful and reassuring.

7.3.2 Permanence versus reversibility of stoma

The question of reversing the stoma was important to several of the participants. Feelings varied among them as to the permanence of the stoma, two appreciated it being there (PT#2, PT#8), another appreciated it but still disliked it (PT#4) whilst another expressed absolute hatred (PT#3). Reversal or hope of stoma reversal was linked with the need to keep positive and have hope for the future. The belief that stoma closure offered hope and signified that life will be returning to normal was evident. Participant #4 captured this as she openly spoke of her fears of the stoma being permanent and never being fully able to accept it, when she stated:

“I know people, there was a lady in the bed opposite and she had it (stoma) for 15 years. She seemed alright about it. I’m only coping with it (stoma) because I’ve got to and it’s knowing it’s only there for a short time that keeps me going. How I would feel about it (stoma) if I had to have it all the time I

really don't know. I dread to think. I don't think I'm ever going too really, 100% accept it". (PT#4, female, 66 years, Diverticular disease)

Whereas participant #2 stated he would deal with the thought of the stoma being permanent if it happened:

"Not sure how I'd feel with the prospect of having the stoma permanently. Physically I think I'd be OK cos I'm doing pretty much now as I would if I was in remission, I guess it's more the psychological aspects, guess I'll think about it nearer the time". (PT#2, male, 24 years, Crohn's disease)

For some bargaining was a way of coping with the situation at the time. Participant #4 expressed her 'dread' of the stoma becoming permanent but could deal with the here and now, knowing the stoma was short term. Participant #2 differentiated between the physical and psychological aspects of the stoma being permanent. He acknowledged the stoma physically but psychologically wished to postpone thinking about how he might cope with a permanent stoma until or if that time came.

Some participants expressed feelings of being in limbo as they waited for stoma closure, as described:

"I don't really see, I mean obviously my parents know but no-body else, I don't really want people knowing really, cos it's personal and if it's only temporary anyway then it's, I can get it like reversed, so that's sort of makes me feel it's not worth telling anyone." (PT#7, male, 19 years, FAP)

"I suppose I feel imperfect you know, though not having a job, no prospects of having a job and through having this bag and all that, you know, no direction like in life, just caught in limbo, its affected me more latterly." (PT#6, male, 61 years, Ca. bowel)

This liminality clearly had an impact on their day to day living with a stoma suggesting this may hinder their journey towards an adaptive lifestyle. This was even more evident if the stoma had been problematic, as clearly illustrated below:

“Twice the bags come off. It was the very first thing I went to, my neighbour said I should go but I just knew something awful would happen. Half way through the afternoon, we were having a lovely tea and catch up, and the damn thing (stoma appliance) burst. I felt wetness against my arm and in horror looked down and my skirt was stained. Thankfully my neighbour brought me back here (sheltered accommodation) immediately, I was devastated, now you see why I’m always touching my tummy, just checking, constantly checking. I’ll be so glad to get back to normal.” (PT#4, female, 66 years, Diverticular disease)

Other participants were anxious as to how life would be once their stoma was closed. They recalled previous surgical experiences and were anxious considering whether their bowel function would return to normal as PT#6 pointed out:

“I’ll be glad to get rid of this (points to stoma), I’ve had a few problems with bags bursting but now I’m worried I won’t have control when I go to the loo normally, you know once this bag has gone”. (PT#6, male, 61 years, Ca. bowel)

The participants expressed a wish for the specialist stoma care nurse not to minimise the impact of the stoma as a way of enabling the individual to cope. This was seen by the participants as a short term coping strategy and did not really allow patients to dislike the stoma if they wanted to. If the stoma becomes permanent the possibility of deep-seated psychological issues may ensue, as explicitly illustrated below:

"I think if they (nurse specialist) could just recognise that you are not happy to have it, the general feeling that I got was that you know, that I was very lucky, that they'd been able to do it whereas really it (stoma) is really the last thing in the world you wanted and you were actually only having it to make someone else happy umm, to maybe to be able to acknowledge that, that you're not happy to have it, cos it's not something that you perceive as an improvement, it's something you perceive as destroying your life but maybe if they could just say . . . 'oh, well, we can actually understand how you feel that you really, really, hate it, and you hate yourself and hate everything about it, but actually in 3 months' time, you know, give it 3 months, give it a day, give it 2 days or 3 days or give it a week and just you know see whether you can actually get used to a little bit more each day and then at the end of the 3 months see if you really, really still feel the same. I think just acknowledging the fact you can just hate everything about the thing (stoma) and not feel grateful cos I don't, I feel quite angry about it. And not to feel bad about feeling angry about it or not to feel that you are ungrateful that the dear old NHS has put so much into you to save your life and you don't think it's worth it." (PT#3, female, 54 years, Crohn's disease)

There appeared to be more emphasis amongst the participants with temporary stomas to have a greater sense of personal control. Managing their stoma both physically and psychologically appeared bearable, knowing that the period of time living with a stoma was limited.

7.3.3 Anticipated stigma

Early on in the interviews most participants stated their life was unchanged since stoma surgery but as the interviewer delved deeper into their experiences, it was evident through their accounts that this was not the case. Reports of experiencing daily practical difficulties when caring for their stoma were common. Being self-conscious was seen to lead to reluctance to seek help and disclose symptoms because of a fear, real or perceived, of being labelled or discriminated against which

in turn validated feelings of shame and disgust. This extract captures the importance of how dignity, secrecy and privacy were in some way shared amongst them all:

“Since arriving here (University) I haven’t told anyone I have a stoma or contacted anyone, I was thinking about it for a while but sort of, I don’t know, it’s scary, you know, people finding out. I’ve not decided which social groups to sign up for yet. I don’t want to get into a situation where I have to explain myself. The thought of telling someone and then get completely ignored next time they saw me.....that would really hurt. I’d rather deal with it (stoma) myself, than for others to find out. I tend to just sort of deal with it, you know, less people that know the better.” (PT#7, male, 19 years, FAP)

The extract highlights the vigilance of a young man fearing possible signs of rejection or being disgraced, utilising this as a defence strategy to avoid social interaction.

Participant #4 demonstrated similar feelings when she acknowledged she did not want others knowing and talking about her:

“I mean you’re not exactly in denial, cos it’s (the stoma) there to see, but I prefer not to talk about it to the people here (sheltered accommodation), I don’t want them knowing.... talking, judging.” (PT#4, female, 66 years, Diverticular disease)

Fear of being ‘exposed’ as having a stoma was a feeling shared by others. Much of these fears related to stoma problems, in particular, an ill-fitting appliance resulting in leakage. Some described curtailing their lifestyle as a preventative measure:

“I have to be careful with what I eat, so I avoid eating anything with skins, especially tomatoes.” (PT#3, female, 54 years, Crohn’s disease)

“I used to love getting on the bus and travelling across town but now having experienced a burst bag, I’ll only go out on a day when my bag is clean and new.” (PT#4, female, 66 years, Diverticular disease)

“Once I know the date of having this (stoma) taken away, I’m going to book a holiday, cos I know I don’t have the confidence to go just now.” (PT#4, female, 66 years, Diverticular disease)

“As I said, I’ll have to think carefully about the social activities I chose to do here (University), just so I won’t have any problems.” (PT#7, male, 19 years, FAP)

Taking precautions to maintain the secrecy and privacy of the presence of the stoma was seen as a continuous task for some of the participants. The challenge here was for them to try and express their needs to the healthcare professional so as to facilitate adaptive behaviour and to minimise the risk of embarrassment, shame and intrusiveness to themselves. Personal control was evident in the choice of whom to tell and when to reveal they had a stoma. Participant #7 later alluded to informing a close friend of the presence of his stoma, highlighting the timing of disclosure to be of great importance to him.

Deciding whether to or when to reveal the presence of their stoma was seen as challenging for some and empowering for others. This participant commented on how empowering it was since informing others remained in her control:

“Well I waited until the time was right, you know, to tell people. I was apprehensive about saying, but I wanted them to know because it meant I didn’t have to keep excusing myself from activities I knew I couldn’t do. It felt so good to have it out in the open.” (PT#5, female, 45 years, severe constipation)

Participant #4 chose to deal with her situation differently. While having described the entire experience of having a stoma as ‘*horrendous*’ might imply she would find

it difficult to disclose she described openly disclosing her stoma surgery to her clients:

“Well they’ve got to know, I’ve told my clients because obviously it directly affects my work; swimming with their dogs. Some are shocked and astonished by what I’ve told them but it’s not about them, is it? It’s about me. It doesn’t affect the treatment I give to their dogs so it shouldn’t affect them.” (PT#3, female, 54 years, Crohn’s disease)

Essentially the stoma is invisible and disclosure is at the person’s discretion.

However, this account highlights how the ability for individuals to deal with trauma or loss varies greatly.

During the interviews participants were invited to talk about their relationships with partners, family and friends since their stoma surgery. They seemed more comfortable to discuss their underlying disease than the stoma, suggesting that they felt threatened or feared the anticipation of being shamed and embarrassed.

Interestingly, when they had gained the courage to disclose their stoma, none of those participants reported being treated differently but they did describe observing others differently wondering if in fact anyone else had a stoma too.

Participant #2 and PT#7 spoke of how they might approach a new relationship. PT#2 stated:

“Crohn’s makes you feel so ill, so it’s nice to feel well again. I’m not really thinking about meeting someone, you know, it’s not top of my list. I don’t like the stoma but I appreciate the reason for it being there and it’s only temporary, so if I did meet someone I’d hope they’d be understanding.” (PT#2, male, 24 years, Crohn’s disease)

This might imply he was not ready to address such issues or that his priority was to consider his physical well-being, meanwhile PT#7 stated:

“I don’t like the idea of doing anything that involves showing me, I mean if I took my shirt off or something, I really wouldn’t wanna, cos the stoma is above my trousers so the bag can be seen like. I talk to girls but I wouldn’t bring them back to my room. I wouldn’t want to do anything sexual like cos that would be a bit strange. I just, it would just bother me”. (PT#7, male, 19 years, FAP)

This extract implies this young man was conscious of the change in his body image as a consequence of stoma surgery; a view shared by others. He displayed concerns regarding physically revealing any part of his body that would draw attention to the stoma. Others expressed fears of rejection as being a ‘blow’ (PT#8) to their self-esteem and self-confidence. Having already perceived themselves as different, the participants had to navigate the choice between revelation and secrecy in terms of how they presented themselves socially; should they pass themselves off as normal and aim to be treated as such, when subjectively they feel different or do they disclose their ‘true self’ and risk associated stigma.

7.3.4 Psychological projection

A few of the participants’ accounts appear to demonstrate a projection of their feelings onto others. This appeared to enable them to rationalise their situation and comprehend the realities of living with a stoma. As illustrated in Table 7.1 at the beginning of this chapter, PT#6 demonstrated this as he recalled working with someone from his past that then triggered his own fears and hatred of the stoma which he projected onto his daughter, as he stated:

"Years ago I had a job as a cleaner and met this lad who had a bag. I just thought crikey how young he was, cos at that time I didn't know you could do things like that. He told me, not that he ever showed me, cos that would have been bad, but he told me a bit about the bag and everything. He told me that he'd had a girlfriend and she seemed OK with it and that's a big thing, you think about, you know, your wife and your family, their disgust. I mean I just think if this happened to my daughter, you know pretty, young, single girl, I don't know she might have coped but I guess we would have been there for her like they are for me". (PT#6, male, 61 years, Ca. bowel)

Whilst another participant projected her emotions onto her pet dog by stating:

"I was more concerned how my dog would react to the stoma rather than my husband. My dog is autistic and I've been surprised by his attitude to it (the stoma) cos he's been well I expected him to be very unaccepting and very difficult and quite bolshie with me but he hasn't, in fact he's been calm and been very accepting of the changes he's had to make." (PT#3, female, 54 years, Crohn's disease)

Describing her stoma as 'gross', she demonstrated great relief when her dog did not seem to mind the stoma, which is perhaps in contrast to her husband who was nonchalantly described as feeling 'OK about it' later in the narrative. It was clear that patients sought acceptance from several sources and it was important for them to know where to get this acceptance from.

Another participant projected her feelings through her family. Reluctant to eat, she rationalises her own deterioration in health. Her underlying sadness is clear throughout her narrative and there is a sense she feels her sons think she may wish to give up. This could be a projection of her own wish to give up which they seemingly articulate for her. She denies this but further on in her narrative she contemplates the end of her life, as highlighted when she stated:

"I'm not eating so well, but I'm a lot older than others I know with one (stoma) and they haven't been through what I've been through. That younger women I met, she's now had it (stoma) reversed and has put lots of weight on..... My sons, they attempt to cook and bring me food that they think I might like. I wonder how they might feel, in my position as they sit there and watch me eat. It's hard. I try but just not got the appetite..... so they say, 'don't give up, mum'. I'm not; I'm just not as strong as I once was." (PT#1, female, 74 years, Ca. Anus)

Projection of feelings in the circumstances of adapting to a stoma may reflect the life changing nature of the disease that resulted in stoma formation, living with a stoma and the psychological difficulties people face. The need to have access to the specialist support was deemed very important, as this statement typified:

"You know your own body, don't you, I mean you know when you don't feel quite right, and I haven't really had any problems. I only have to call and say I have a problem and they'd (stoma nurse) book me in for an appointment or come a see me here (sheltered accommodation) straight away." (PT#4, female, 66 years, Diverticular disease)

A challenge for patients was to recognise when they needed help and to use the resources of the specialist stoma care nurse appropriately. Some participants (PT#7, PT#1, and PT#4) admitted they felt unable to communicate openly and share their concerns. This was confounded by the difficulty to talk about the stoma and associated feelings (PT#7). However as previously recognised, once concerns had been disclosed there was a sense of empowerment and sharing and the feeling of being able to *"get through this together"* (PT#5).

7.3.5 Worthwhile sacrifice

Whilst some participants were negative towards their stoma, others were more positive. Previous themes have highlighted the significant difficulties a newly created stoma represented for the participants. A key aspect for them was the feeling of unhappiness with regards to their change in body image combined with recognition that this change had provided a cure or relief from a debilitating illness; consequently, their feelings were mixed. There was a sense of now that they were living with a stoma; things weren't so bad, as captured by participant #2 who expressed relief to feel well again:

"I think at the moment it's nice just to feel well, you know, it's been such a long time, so you know it's a worthwhile sacrifice." (PT#2, male, 24 years, Crohn's disease)

For others, although the dislike towards the stoma was apparent, life had taken on a new meaning leading to a greater need to live. Good quality of life was viewed within the context of illness and other aspects of life became equal if not a greater priority than the physical limitations of having a stoma, as participant #6 captured when he contemplated his existence:

"Just everything seemed to hit, being made redundant, wondering if I'll ever work again and cancer, you know, how long, what about my young family, my little boy my young daughter, finances and all that and to top it all it didn't seem that natural having to look at your intestine sticking out of your stomach, it just repulsed me at one point I thought I'd rather die than have it permanently. I think that the things in life that were important to you or you thought important, aren't as important I want to stay alive. The cancer is out and this is (pointing to the stoma) temporary, I have hope for the future, so it's worth putting up with." (PT#6, male, 61 years, Ca. bowel)

This narrative demonstrated that his perception of his quality of life with a stoma may have shifted. Initially he was devastated by the cancer diagnosis and repulsed by the subsequent stoma formation. As he adapted to his situation he appeared to change his values, suggesting the opportunity to re-evaluate had prompted coping mechanisms to accommodate change. Learning to adapt to this change was twofold for several participants; feeling unhappy whilst living with the stoma while knowing that their quality of life had improved as a result.

Participant #1 rationalised the new lease of life bought about by the stoma but there was underlying sadness as her loneliness and perceived loss of femininity were poignantly demonstrated:

“About 27 years ago I survived cervical cancer, now this I was lucky though, cos at one point they said I might not be able to have a stoma. You know at first you shed a tear cos of how the stoma makes you look and feel. Losing the ability to have sex went years ago and I’ve put up with my husband’s infidelity. He says I look thin and scrawny cos I’m not eating but as I get stronger I’m hoping I can get back to some normality, so it’s worth it in the end.” (PT#1, female, 74 years, Ca. Anus)

As the participants demonstrated the adaptation to their stoma, they may not have been happy with their situation but had found ways of coping with it. During the interviews the participants acknowledged a number of difficulties relating to living with a stoma. However, these were felt to be less significant when interpreted within the context of their underlying condition and associated risk of disease related mortality as the next section illustrates.

7.3.6 Sense of achievement

Participants described the significance of their family and close friends during the process of recovery, emphasising the importance they had in facilitating the milestones of their recovery such as stoma care self-efficacy and re-establishing social contacts, as PT#8 illustrated:

“My wife and I are what we call ‘foodies’. We love trying out different foods and wines at many different restaurants. Before my operation we weren’t dining out at all, cos the pouch was so unpredictable, a mouthful and I’d be off to the loo. So we stopped going. I can tell you, this knocked my confidence dreadfully. But now continuing to get better and being able to enjoy a vast array of food has been a tremendous achievementjust being able to socialise again, it’s just getting that feeling of normality back.” (PT#8, male, 64 years, Ulcerative colitis)

Regardless of disease and its potential impact on their lives, the presence of the stoma offered the participants time to re-evaluate what was important to them. They described a determination not to let the stoma ‘beat them’ (PT#1, PT#4 and PT#8). So despite previously describing significant stoma-related difficulties, they, in part, were able to balance the amount of perceived control they actually had over their stoma with the demands of other aspects of their life and reflected upon their recovery, as captured by the following:

“I guess you look at things differently, when you have responsibilities, you have to think of others as well as yourself, and other things as well as yourself, and maybe choose to do things you wouldn’t usually choose to do just for yourself, it’s a bit like having a purpose or needing a purpose to survive.” (PT#3, female, 54 years, Crohn’s disease)

“It’s like I’ve been given another opportunity, so I’m gonna get my life back together, whatever it takes.” (PT#1, female, 74 years, Ca. Anus)

“The need to provide for your family is very important; it’s a valuable role and not being the bread winner at the moment has been difficult to adjust too. On the other hand, not working, spending time with my family, cooking, taking the kids to school and pottering here and there has given me the opportunity to re-evaluate life and what is actually important.” (PT#6, male, 61 years, Ca. bowel)

“They’ve asked when I’ll be back and able to work. It’s nice to know they want you but this has given me time to think about what I want from life. You hear people talk about work-life balance, I think it’s time for me to consider mine.” (PT#5, female, 45 years, severe constipation)

Furthermore, participants described how maintaining contact with family and friends who they knew prior to their stoma surgery provided reassurance and helped them recognise their previous self-identity. Such outcomes can enable patients to consider that they are disease free, allowing them to reflect upon personal fulfilment, find meaningful pursuits in life and have a greater appreciation of life. As adaptation takes place symptoms begin to decline, and strength and vigour increase, patients may see their recovery advancing.

7.4 Summary

Phase one of the study explored the adaptive journey of the patient with a newly formed stoma highlighting the challenges they faced. Eight patient participants were interviewed. Their accounts capture a picture of the real life experiences of living with a stoma. Experiences and the ability to adapt evidently differed from one individual to another. The findings, presented as themes, characterize an aspect of how individuals adapted to stoma surgery. A series of disruptions to their lives have been described; learning to cope with uncertainty, preserving hope for their future, living in limbo, concerns as to how they might conceal their stoma, how they might

cope with their stoma or how they might curtail their lifestyle to accommodate the stoma.

These features are mirrored in others studies (Sunderland et al, 1952, Orbach and Tallent, 1965, Follick et al, 1984, Kelly, 1992, White and Unwin, 1998, McVey et al, 2001, Borwell, 2006, Haugen et al 2006, Danielsen et al, 2013b) and reinforce the profound effect living with a stoma has on an individual. The data also demonstrate that patients acquire substantial amounts of information on separate occasions from a variety of health care professionals. This requires consolidation of information into a level of knowledge and skills that will enable them to live with their stoma confidently and competently. This requirement is both challenging for the patient and the specialist stoma care nurse to fulfil.

Specialist stoma care nurses are ideally placed to pick up on the cues signposting the challenges faced by the patient living with a stoma. Working with the given cues, they are in a position to facilitate the adaptive needs of patients by tailoring the necessary information for the individual. Equipped with specialist knowledge and skills, the specialist stoma care nurse is in an ideal position to deliver this information in a manner that is comprehensive to the individual patient.

The complexities of navigating specialist knowledge and skills by the stoma care nurse to facilitate the challenges faced by patients are explored in phase two of this study. This was aided by developing the patient narratives from phase one into

vignettes. The vignettes were used to stimulate discussion amongst the nurse participants in the focus groups.

7.5 Analysis and findings from Phase 2

Thirty-nine specialist stoma care nurses were purposefully selected to take part in one of a series of seven focus groups over a period of five months (See Table 6.4). The number of nurse participants per focus group ranged from three to seven. The clinical experience of the nurse participants relating to stoma care and/or gastrointestinal nursing varied from three months to 23 years; all having a common goal to support and advise patients with stomas. During the course of the focus groups, vignettes representing each theme were discussed twice (See Table 7.2). Themes were not disclosed to the nurse participants during the focus group discussion. In addition to discussing the vignettes the nurses provided numerous examples of clinical scenarios from their own practice areas which they acknowledged as being meaningful to their practice. Following transcription of the focus group discussions, stage 2 of the analysis took place (See Figure 7.4).

The findings from phase 2 were subjected to a thematic analysis resulting in five emerging themes; skilled know-how, understanding self, hurdles to accommodate, communication skills and uncertain ground. An example of the analysis is shown in Table 7.3. The findings are presented as highlighted by the nurse participants (See Figure 7.5) and are supported by the notes taken in the journal by the observer at the time of focus group as declared in Chapter 6.

Figure 7.4 - Stage 2 of the analysis

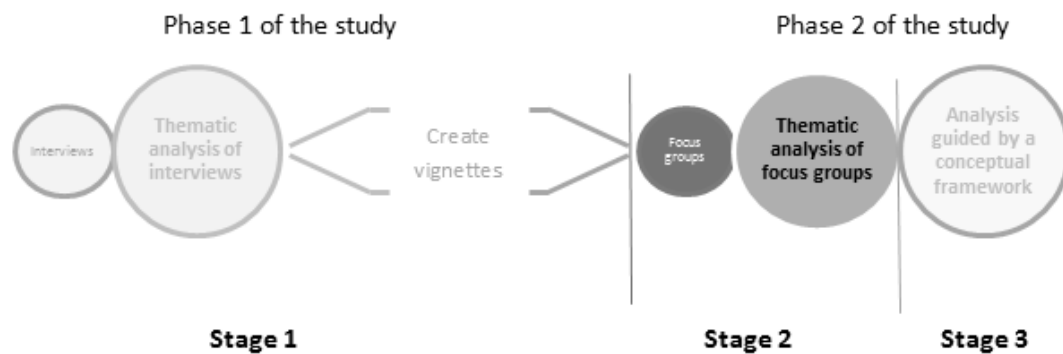


Table 7.3 - Example of analysis; theme 'Skilled know-how'

Nurse participant narrative	Narrative interpretation	Meaning	Theme
<p><i>"We probably need to have a bit more information at knowing what sort of stage cancer it was. Was it a T2 or T4, then you'll know how to prepare him in sort of dealing with it? A T1 or T2 tumour with no Mets and no spread you can really sort of lay on the positivity line and push him forward and give him the encouragement and enthusiasm to move forward". (FG#5, NP26)</i></p>	<p>More information is needed before giving patient appropriate information regarding their cancer pathway</p>	<p>Knowledge (background /foreground) Experience Experiential learning Clinical practice Clinical judgement Decision-making</p>	<p>Skilled know-how</p>

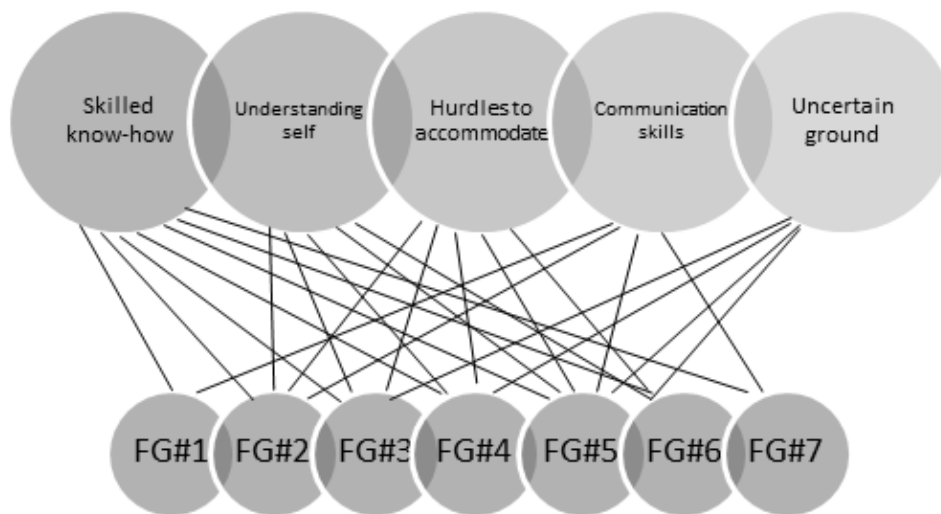
Table 7.2 - Themes from phase 1 and representing vignettes

Theme and number	Vignette 1	Vignette 2	Vignette 3	Vignette 4
1. Seeking assurances	54 year old female with loop ileostomy for Crohn's Disease, <i>"This is such a horrendous experience and I fully understand that for some people it changes their lives for the better and they can cope with it and everything it entails and maybe even their lifestyles can incorporate it much easier but I know for myself that it just doesn't work, I don't think it's solved the problem, it fact it has created more problems, I just feel it has ruined my life, my whole life, my business, everything. I only agreed to have it (the stoma) done if the surgeon promised to make the stoma temporary". (PT#3)</i>	45 year old female with permanent colostomy for severe constipation, <i>"The stoma wasn't placed where we (stoma nurse and patient) agreed. At the pre-assessment the stoma nurse marked 2 points on my tummy, checking for creases, belt lines and all that and they get you to stand up and sit down to make sure it's (the stoma) is in a good position and all this happened before surgery and then after, it was right in a crease. She (stoma nurse) even took photos and spoke to the surgeon, cos I had lots of creases from previous surgery. Now I know she didn't promise where it (the stoma) would be placed but you'd think having gone to all that bother it would at least not be in a crease". (PT#5)</i>	64 year old male with permanent ileostomy ulcerative colitis, <i>"I've had my pouch for 20 years or so and it did me pretty well. Over the past 5 years things have begun to deteriorate so I was going to the loo more frequently and I was getting increasing pains in the stomach and the pouch. I was having to get up at night cos of the anal discharge and going out for meals became impossible. It just got worse and worse, until I was almost house bound. I spoke in detail to my surgeon and after some thought decided to have the pouch removed because she promised my symptoms would stop and my quality of life would improve, don't get me wrong I am much better but I've still got the wretched discharge. I'm beginning to wonder whether the pouch was removed at all". (PT#8)</i>	
2. Permanence versus reversibility of stoma	61 year old male with temporary ileostomy for bowel cancer, <i>"I suppose I feel imperfect you know, though not having a job, no prospects of having a job and through having this bag and all that, you know, no direction like in life, just caught in limbo, its affected me more latterly." (PT#6)</i>	24 year old with temporary ileostomy for Crohn's disease, <i>"Not sure how I'd feel with the prospect of having the stoma permanently. Physically I think I'd be OK cos I'm doing pretty much now as I would if I was in remission, I guess it's more the psychological aspects, guess I'll think about it nearer the time". (PT#2)</i>	66 year old female with temporary colostomy for Diverticular Disease, <i>"I know people, there was a lady in the bed opposite and she had it (stoma) for 15 years. She seemed alright about it. I'm only coping with it (stoma) because I've got to and it's knowing it's only there for a short time that keeps me going. How I would feel about it (stoma) if I had to have it all the time I really don't know. I dread to think. I don't think I'm ever going too really, 100% accept it". (PT#4)</i>	54 year old female with loop ileostomy for Crohn's Disease, <i>"I hate absolutely everything about it (the stoma), the fact that you've got your insides sticking out, that you have to collect everything that comes out of it (stoma), all your waste products, all come out of it, it is perceived by other people as either being something quite crudely amusing or just unnatural. I don't want to live with this (stoma) any longer than I have too". (PT#3)</i>

Theme and number	Vignette 1	Vignette 2	Vignette 3	Vignette 4
3. Anticipated stigma	19 year old with temporary ileostomy for Familial Adenomatous Polyposis, <i>"I haven't told anyone here (University) um... I was, um, thinking about it for a while but sort of...it's, um...., well, I don't know..... she's, um (stoma nurse), well she, um, has given me a number for someone um...but...um....well, it's sort of I don't know, well, um, I wouldn't know whatum, to do if I needed help here, umm..well, I'd probably ring home, you know and um, well say, um, look I'm in trouble or something, I'd be OK, you know, I feel like I'd probably be OK." (PT#7)</i>	66 year old female with temporary colostomy for Diverticular Disease, <i>"It's been a very traumatic experience, when I had the stoma at first, actually I think I was in shock, I felt numb, I mean you're not exactly in denial, cos it's (the stoma) there to see, but I prefer not to talk about it to the people here (Sheltered accommodation) I don't want them knowing.... talking." (PT#4)</i>	54 year old female with loop ileostomy for Crohn's Disease, <i>"Well they've got to know, I've told people because obviously it affects my work. Some are shocked and astonished by what I've told them but it's not about them, is it? It's about me. It doesn't affect the treatment I give to their dogs so it shouldn't affect them". (PT#3)</i>	
4. Psychological projection	61 year old male with temporary ileostomy for bowel cancer, <i>"I just think if this happened to my daughter, you know young, single girl, I don't know she might have coped but I guess we would have been there for her like they are for me". (PT#6)</i>	54 year old female with loop ileostomy for Crohn's Disease, <i>"I was more concerned as to how my dog would react to the stoma rather than my husband. My dog is actually autistic and I've been surprised by his attitude to it (stoma) cos he's been, well I expected him to be very unaccepting and very difficult and quite bolshie with me but he hasn't, in fact he's been quite calm and been very accepting of the changes he's had to make and in his own funny little way quite supportive which has helped. I know they sense something's different but expected him to attack it (stoma), you know, being an alien thing to do with me. Cos generally he's always by my side when I change the bag he's never grizzled once, he's just been very, very calm. He's accepted not being able to be on the bed at night, so he lays on the floor, my side".(PT#3)</i>		

Theme and number	Vignette 1	Vignette 2	Vignette 3	Vignette 4
5. Worthwhile sacrifice	74 year old female with permanent colostomy for cancer of the rectum, <i>"About 27 years ago I survived cervical cancer, now this, I was lucky though, cos at one point they said I might not be able to have a stoma. You know at first you shed a tear cos of how the stoma makes you look and feel. Losing the ability to have sex went years ago and I've put up with my husband's infidelity. He says I look thin and scrawny cos I'm not eating but as I get stronger I'm hoping I can get back to some normality, I'm so it's worth it in the end".</i> (PT#1)	24 year old with temporary ileostomy for Crohn's disease, <i>"I think at the moment it's nice just to feel well, you know, it's been such a long time, so you know it's a worthwhile sacrifice".</i> (PT#2)	61 year old male with temporary ileostomy for bowel cancer, <i>"Just everything seemed to hit, being made redundant, wondering if I'll ever work again and cancer, you know, how long, what about my young family, my little boy my young daughter, finances and all that and to top it all it didn't seem that natural having to look at your intestine sticking out of your stomach, it just repulsed me at one point I thought I'd rather die than have it permanently. I think that the things in life that were important to you or you thought important, aren't as important I want to stay alive. The cancer is out and this is (pointing to the stoma) temporary, I have hope for the future, so it's worth putting up with".</i> (PT#6)	19 year old with temporary ileostomy for Familial Adenomatous Polyposis, <i>"Having a stoma, it's, um, not really affecting my life but it's sort of just having it, just thinking about it,... well it's quite annoying really. It.. um, does mean, well, you know, the polyps, well they've gone and well there's less chance of me getting anything worse, you know and get cancer or something. So it's (the stoma), well it's only there for a short time, so it's kinda OK.</i> (PT#7)
6. Sense of achievement	61 year old male with temporary ileostomy for bowel cancer, <i>"The need to provide for your family is very important, it's a valuable role and not being the bread winner at the moment has been difficult to adjust too. On the other hand, not working, spending time with my family, cooking, taking the kids to school and pottering here and there has given me the opportunity to re-evaluate life and what is actually important".</i> (PT#6)	64 year old male with permanent ileostomy for ulcerative colitis, <i>"My wife and I are what we call 'foodies'. We love trying out different foods and wines at many different restaurants. Before my operation we weren't dining out at all, cos the pouch was so unpredictable, a mouthful and I'd be off to the loo. So we stopped going. I can tell you, this knocked my confidence dreadfully. But now continuing to get better and being able to enjoy a vast array of food has been a tremendous achievement, just being able to socialise again, it's just getting that feeling of normality back".</i> (PT#8)		

Figure 7.5 - Mapped themes to the focus groups



7.5.1 Skilled know-how

The nurse participants shared the view that skilled know-how was essential to any claims to competency as a specialist practitioner. Skilled know-how related to their specialist knowledge, specialist clinical skills and expertise. Specialist knowledge of a patient's underlying disease and treatment plan, the surgical procedure, potential stoma complications and expectations of recovery from stoma surgery were described as a fundamental requirement to fulfil the role as specialist stoma care nurse:

"It's about having a sound knowledge base, so that you can provide patients' with the information they need, so like knowledge of the disease, the surgery, the stoma, it's (stoma) complications, additional treatments, like chemo and basically how it's going to affect them (patient) and their family." (FG#1, NP2)

"They (Theme 3, vignette 2) might never get to live a normal life, sharing all that we know, our knowledge and experience is so important. We've got to make it better for them, to enable them to cope as best that they can. Having the basic stoma care knowledge, the condition, type of stoma, complications It's all essential if we are to understand their (patient) needs." (FG#4, NP18)

“As a CNS you’ve got to have the right attitude, knowledge and skills.” (FG#1, NP5)

Equipped with their specialist knowledge and skills there was a sense that the nurses wanted to make a difference to their patients and provide high quality stoma care, as captured by this nurse:

“I don’t want to be this overpowering person, definitely not. I just want to just be a part of making their life much, you know, better and more comfortable and, you know, just making a difference, because you get, that’s where you get your job satisfaction, because not, my husband says to me, ‘I’d love a job like yours, you know, where you’re actually making a difference to somebody, I don’t make a difference to anybody. I just go in, just do my job and come home. You don’t.’ He said, ‘You actually love your job.’ He said, ‘You actually want to go to work,’ he said, ‘I don’t.’” (FG#4, NP24)

The elements of expertise that stood out amongst the discussions related to knowing the patient and information giving. The need to know the patient, as a specialist, appeared to give the nurses an opportunity to develop a deeper understanding of the patient as a unique individual and hence build towards a therapeutic relationship.

Establishing a therapeutic relationship was seen as an important pre-requisite to facilitating the patients’ recovery. Developing such a close relationship and preserving it was cited as a key factor for becoming a specialist stoma care nurse, as illustrated:

“That’s the reason I wanted to be in this role, I think we have a special relationship with our patients. I think we are privileged to be part of their lives. I think, in terms of special, I guess like other nurse specialists we see the journey of the patient and their family and we get the opportunity to know them, you know, get to know them as a person. They share some of their most intimate times with us and that’s a privilege. It’s a very special relationship we build up.” (FG#3, NP14)

“Having a stoma is sort of like a lifelong, well for some any way, and so those people, whether it’s sort of, you know, in two months’ time or in twelve years’ time, could

potentially reach a point that actually yes they need advice, support, something may happen – their partner might die and their world might start collapsing. That’s what I like about my role.” (FG#5, NP27)

“I think as a stoma nurse you’re there before, during and after their surgery. You see them at their most vulnerable, you guide them and offer support and advice. It’s not just the stoma, but it’s how they recover and you’re part of that special journey with them.” (FG#2, NP7)

“We have a special relationship with our patients. We see them (the patient) from initial diagnosis all through the whole journey. You know, everything right through to start to finish, and from my point of view, that’s such a special role to be able to go through that journey. You end up building a massive rapport and support system for them.” (FG#3, NP17)

Specialist knowledge was linked to their ability to make clinical judgements. Using the vignettes as examples, the nurses demonstrated this, expressing a need to know the wider context of a patient’s situation enabling them to draw upon their specialist knowledge and create a plan of individualised stoma care, as illustrated below:

“It’s all about whether they’ve (the patient) has been given the full information. I mean was this gentleman (Theme 1, vignette 3) told there was a possibility that his pouch wasn’t going to be removed or it might just have been too difficult a surgical procedure. You’ve got to have this sort of information before you can discuss this any further.” (FG#1, NP2)

“We probably need to have a bit more information at knowing what sort of stage the cancer it was. Was it a T2 or T4, then you’ll know how to prepare him (Theme 5, vignette 3) in sort of dealing with it? A T1 or T2 tumour with no Mets and no spread you can really sort of lay on the positivity line and push him forward and give him the encouragement and enthusiasm to move forward.” (FG#5, NP26)

Being a specialist stoma care nurse was seen as extremely rewarding. Striving to understand the challenges faced by patients with stomas, supporting and guiding them throughout their recovery were evident through the nurses’ narratives. A shared view of demonstrating their

specialist skilled know-how was related to being valued and respected by other healthcare professionals.

However, although not universally felt, there was a sense of immense pressure of the responsibility and accountability felt to deliver and maintain expert knowledge and practice. This often led to stress and anxiety and these feelings led to apprehensions in relation to clinical judgements and concern that subsequent actions might be challenged by healthcare colleagues, as these narratives typified:

“There’s an expectation we’ll fix all and I love the buzz when you’re busy and the ward staff are having difficulties keeping a fistula bag on or there’s a dehist wound bag, and you come up with a plan that sorts the problem. Relief on the nurses faces as well as the patient, that’s greatyou just hope you can repeat it next time!” (FG#7, NP38)

And

*NP13: “they (patients) expect us to know everything”,
NP15: “yes, have an answer for everything”,
NP16: “yeah, it’s frustrating in some ways when you can’t solve all the problems they have”,
NP17: Yeah, sometimes you feel that you almost have to save the world!” (FG#3)*

This was linked to a lack of confidence to deliver specialist knowledge to a high standard, as conveyed by this nurse:

“Seeing I’ve just started, well, it’s quite difficult for me, because I’ve got like, if someone just asks me something and I don’t know the answer, I’ve got to make sure that I go back and read about things and I think with me, I think there’s more of a delay. I’ve got to like refer on to someone else, whereas if they’re more experienced, people can give answers straightaway. It makes me think patients don’t trust the information I give them cos it’s not instant.” (FG#3, NP13)

“I feel I’ve learnt so much in such a short space of time that, I do feel I have made a difference, certainly the brand new patients; they’re the ones I’ve seen pre-op. The

ones that are already established, sometimes it takes a bit of time for them to get to know me, you know, to trust me. But I find the patients who are brand new patients, they trust you from the beginning. And they take what you say, you know, the amount of 'thank you' cards we've had." (FG#3, NP13)

Continuity of care was seen as '*crucial to the patient's ability*' (FG#7, NP39) to adapt to a new stoma, highlighting co-ordination of expert knowledge, provision of patient teaching and continued support both pre- and post-operatively seen as essential if patients were to adapt to stoma surgery. Fragmented care was alluded to, as participants felt that the knowledge amongst nurses and allied healthcare professionals varied greatly, often leading to conflicting advice and confusion for the patient, as illustrated:

"It's difficult as well because sometimes there's little continuity. You could get five, six, seven different disciplines going in to this person (Theme 2, vignette 1) and they'll (the patient) latch to somebody and only hear what they want to hear. You can see what they're getting at, because you do find some tell them differently, because we all work very differently. So that's quite difficult, but I suppose it's recognizing that with that person (Theme 2, vignette 1), you know, if we could allow some continuity it would make the information we give be a tad clearer and hopefully he'd understand." (FG#1, NP4)

Possessing specialist knowledge, skills and expertise were seen as important in order to connect with the patient. This knowing came across as supportive, guiding, individualised and comforting; the nurses' narratives support this. Knowing the patient and developing a therapeutic relationship required an understanding of themselves both professionally and personally, as the next theme indicates.

7.5.2 Understanding self

By knowing themselves better and understanding 'self', the nurse participants demonstrated the ability to understand their strengths and weaknesses, sharing the view that this has helped them develop in their role as a nurse specialist as shown:

"If you can understand yourself then you can learn from your actions, you've got to realise what you can and can't do, you know. So if you can see what you did and why you did it, you can learn from the experience. I think if you're not able to reflect and learn from yourself, then you're never going to be good at anything really, particularly, because you're never going to learn and then become better and better at what you're doing." (FG#4, NP20)

"Being able to look at yourself and learn from yourself is so important. I think if you're not able to reflect and learn from yourself, then you can't develop in your role as a specialist nurse. It's a skill, you know, to look at yourself, you know, and change; it takes courage too." (FG#3, NP17)

Throughout the focus group discussions, it was evident that reflecting upon their practice acted as a major contribution to developing their role as a specialist nurse. Several of the participants saw reflective practice as a way of learning from their experiences and developing their expertise. Described as a *"self-directed approach"* (FG#7, NP36), the need and ability to reflect upon practice was seen as an important learning tool allowing them to develop knowledge further, as outlined below:

"I think you need to reflect on your practice. I think you've always to learn from it, but you can never think that, like in the scenarios, you can't always say that, 'I'm really good, because everybody has told me,' you have to sometimes take a step back and think, because you do come out of situations and think, 'That was awful, that was horrendous.' And you have to learn from it. And then think, 'Well next time I will do it differently.' And be realistic that you will have days where you come in and think, 'I can't believe that I just said that.'" (FG#6, NP31)

Reflection also helped them cope with stressful situations. Those who appeared to cope best were those who were self-aware, took care of themselves, kept work in perspective, and maintained an emotional balance between themselves and the patient, as demonstrated:

"We all face stressful situations. I guess we're lucky though cos we meet as a team regularly and talk about our individual caseloads and what we are currently having difficulty with, talking to like-minded peers, it helps keep that emotional stability between you and the patient." (FG#5, NP27)

The nurses were also seen to reflect on their life experiences as well as those from clinical practice; these were also considered to be of value. A few of the nurses explained that the more experience they had in colo-rectal nursing, the more comfortable they felt in not always having all the answers. They also spoke of their own experience of having a family member who was living with cancer or who had died of the disease and how that experience had affected their approach to nursing care. As they referred to their experiences, some difficult and some painful, they were able to demonstrate some valuable insights as illustrated:

"It might sound old fashioned but I try and get colleagues to think about situations as if it was their own mum or dad. And I've actually used that with a consultant and said, 'If that was your dad, would you be happy that your dad was going home and weeing all over your mum's carpet?' Because actually that's what's happening.' And then the patient wasn't sent home. You know, my mum got lung cancer last year. And she died in May and it was the hardest time of my life. And being on the other side of that was really difficult." (FG#6, NP34)

"And when patients have rung up saying 'I've got to wait two and a half weeks to see the oncologist. I don't think I can wait that long.' And then, you know, exactly the same situation happened with my dad, and, you know, I'm thinking, 'Oh my God, it's a month.' And, you know, I was on the phone to the oncologist's secretary saying, 'You've got to see my dad next week,' and I think, you know, so when patients ring up and say to me, 'I'm not seeing so and so, can't see the consultant for seven and a half

weeks,' I think, 'Oh my God you poor thing,' you know. 'We've got to get this sorted.'." (FG#4, NP22)

"What was hard for me was what my whole nursing philosophy was based on – my dad died suddenly when I was a child, so I was – he went off, gave us a kiss and never came home. And I always felt that was the worst thing, and it was far better to get this diagnosis that you're going to die and you could say all those lovely things to patients, you know, to your family. And I've fostered that throughout my whole nursing career with terminal patients, I've fostered those conversations. But my sister, when she was dying of breast cancer, she was having none of it, and it just completely – I don't know, I was saying to her things like, 'Aren't you tired of being ill?' And she said, 'No, because when I get better and I'm at home, we'll laugh about this.' And I'd say, 'Whatever,' and she just would not – and she didn't allow me to have that conversation. And it just threw me, because I thought all these times I've been saying, 'You need to sort of have that conversation.'" (FG#1, NP5)

"My last conversation with a really good friend, one of my best friends, in a hospice, was looking through holiday brochures, pretending we were about to book a holiday together, because she would not, she would not talk about it. 'Well where shall we go this summer then, what are we going to do, you've got to bring those brochures in.' So that's exactly, that was my last conversation with her, of where we were going to go that summer on holiday, which I knew we were never going to take.....Being on the other side makes you reflect on how you offer patients support in similar situations." (FG#7, NP38)

Commenting on these reflections the nurses pointed out that what they had learnt was not something that could be taught from journals or attending study days and courses implying learning from experience was *"unique and priceless"* (FG#1, NP5). Sharing such experiences was also seen as important for the development of others and this opportunity was reported to evolve through clinical supervision.

Clinical supervision was offered (and funded) to the nurses by their employing NHS Trust or through private consultation. Most received clinical supervision monthly either on a one-to-one basis or as a group/team. Those receiving supervision reported the positive effects of receiving it, describing how being able to discuss clinical issues in greater depth and reflect upon practice, increased their self-awareness and personal growth. Sharing and learning

from practice with other specialist stoma care nurses was seen to reduce stress as shared care seemed to benefit difficult clinical situations, as outlined:

“We’ve had some really sad cases recently, and it made us, as a team, talk about what happened in two of them. I know with this young chap I was feeling particularly helpless, you know, you use up all your resources to try and solve the issue but they didn’t work; and then where. As a team this is what we discussed. It was good to know others were feeling the same and then actually you know you couldn’t have done any more. If others are struggling and can’t think of any other solutions then you know you’ve done your best. It’s good to have that team support.” (FG#1, NP1)

Reflecting on their practice gave them a greater understanding of their actions.

Opportunities to reflect were seen to promote personal attributes, characteristics and expertise fundamental to their role as specialist stoma care nurses. Such opportunities were valued offering clarity of boundaries at both a professional and personal level. The ability to reflect and value reflection was captured by the following:

“It’s all about sharing experiences, listening to others, seeing and learning something new in practice, helps me develop my skills towards becoming competent in my practice.” (FG#2, NP9)

“Sharing with others, your experiences, reflecting back on what you’ve done and see if you can do things better, it helps develop your own skills and value yourself, that’s important too.” (FG#7, NP37)

“But also practical problems arise a bit further down the line as well. And I used to work in a hospital where they got one home visit and that was it. ‘Pick up the phone if you’ve got a problem.’ And it was so nice for me professionally to move to a hospital where we had so much more autonomy. And, you know, everyone, even if they’ve had their stoma decades, they can have an annual MOT if they want it, they don’t have to obviously. But it just made me reflect on what I see was now an incomplete service that I was offering previously, because we do see a lot of problems, both practical and emotional and psychological and psychosexual. And they weren’t really addressed where I worked before.” (FG#6, NP28)

Understanding self was seen to enhance therapeutic relationships (FG#3), offer clarity of role (FG#2, FG#3, FG#5) as well as determine role boundaries (FG#5, FG#6). The participants felt being self-aware underpinned good nursing practice and was essential for establishing effective and therapeutic relationships, as described:

“Good nursing care, well it’s all about a balance between being personal enough, you’ve got to give something of yourself to the patient in order to engage with them and building up that relationship.” (FG#3, NP15)

The ability to recognise personal strengths and limitations enabled participants to identify and begin to understand their emotions and the influence this had on their performance, as illustrated:

“It’s your ability to recognise your limits and cope yourself. We’ve all got levels at which we have a breaking point. So we know when we’re stressed out, we know when we need to take a step back. Some people don’t, I suppose, and that’s when they go over the edge, don’t they? But it’s knowing how to deal with things and it’s that outlook on life and it’s your own perception of life, as what’s going on as to how you deal with things. What would be devastating for me, might not be devastating for another person sitting next to us.” (FG#3, NP17)

The nurses spoke of being self-aware and understanding of self as crucial to maintaining healthy therapeutic relationships with patients. The essence of this was to understand self within the context of clinical practice. Without this understanding the nurses described how it was difficult to understand the needs of others and consequently the needs of patients undergoing stoma surgery. Some aspects of self were challenged by the provision of stoma care within their organisation. These were viewed as hurdles to accommodate; as illustrated in the following theme.

7.5.3 Hurdles to accommodate

The hurdles reported by the nurses related to the service provision for stoma care within their employing NHS Trusts. These included lack of continuity of patient care (FG#2, FG#4, FG#5, FG#6), organisational constraints (FG#5) and initiatives (FG#6) as well as lack of resources (FG#2, FG#3, FG#6)). Feelings of frustration were evident as some nurses reported constraints put upon them with regards to the service delivery. Pressures were also felt, having to constantly demonstrate their worth to line managers (FG#3, FG#6), when clearly all the nurses wanted, was to deliver a high standard of stoma care to their patients.

Three of the nurses within FG#6 (NP28, NP29, NP31) spoke of how they, as a team, were compelled to re-configure their workload to comply with their employing Trust's new initiative *"back to the floor clinical days"*; potentially jeopardising patient care. As one of them explained:

"We are currently looking at the service we offer. There's four of us in the team and we've been told that one of us will have to work on the ward, one day a week; taking it in turns. There's also talk of weekend cover. It's really hard cos we know it will affect the service we currently offer. We've already reduced the number of follow-up visits they (patient) get at home, so it looks like we'll need to reduce this even further. It's really not what we want to offer but we'll have no choice." (FG#6, NP29)

Connecting with patients was seen as an important aspect of their role and any disruption was seen to prolong the development of their nurse-patient relationship and possibly delay the patients' recovery. Without this some nurses implied patients *"coped alone"* (FG#2) often leading to a more complex problem for them to deal with, as captured by this nurse:

“I saw this chap once, he came to clinic on the bus, no bag, just a towel over his stoma cos he couldn’t get a bag to stick. He should never have coped alone. His skin was red raw and he thought this was normal. He felt so low about the whole situation. It took a while but after reviewing his stoma care technique, products and general lifestyle I was able to sort the problem for him. I think he constantly worries that this will happen again.” (FG#2, NP12)

Recent changes to patient recovery programmes were reported to reduce preparation and in-patient time for patients undergoing stoma surgery. As a result, the nurses implied these changes required patients to prepare for surgery with a decreased amount of input from them as specialists. There was also an expectation for the patient to demonstrate stoma care self-care fairly quickly, as illustrated:

“This chap I’ve got in hospital at the moment, he’s on the enhanced recovery programme..... Diagnosed with bowel cancer 2 weeks ago, he’s now had surgery. I saw him once before surgery, he asked all the right questions and we went through everything. He tried the practice pack, put a bag on at home on his own but said everything felt fine. I thought great, he’s done well. Post-op, I can’t believe how he is. I say, ‘Let’s try removing your bag today’, so I takes off the drain bag and ‘What are you doing?’ he says. He just looked so befuddled and in such a mess. He just can’t get his head into gear of what’s going on..... It’s just all too much for him too soon. I don’t want to rush him but I’m expected to discharge him by the weekend.” (FG#2, NP7)

Reporting a lack in the continuity of patient care referred to changes in the dynamic of their role or team and multidisciplinary approaches to care. There was a sense that a lack of continuity of care also contributed to challenging the development of a good nurse-patient relationship as well as sending mixed messages to the patient, as highlighted in FG#4:

“Well we’re not the only one’s offering patient’s advice. They get very confused with whose advice they should follow, you know, dietician, physio, Macmillan. This patient (Theme 5, vignette 1) sounds like she’s got lots of psychological issues, you know, she’s had cancer before, husbands not interested, sounds like she just needs a cuddle. And with all of us (healthcare professionals) going in and saying what we

think is best, when all she wants is someone to talk too. It is difficult, but it's about recognizing the needs of that person, so that there is some continuity." (FG#4, NP22)

This blurring of boundaries with other healthcare roles was also recognised in other focus groups (FG#2, FG#6). It was felt that mixed messages would lead to the patient feeling frustrated and confused, and maybe lead the patient to make decisions regarding their health on their own. One nurse reported the recent change to her role, implying the continuity with her caseload had changed:

"Now that I manage the team my clinical work has reduced. My clinical commitments are now down to about, one and a half, two days, and that's having to cover two sites as well. I was doing one day at one site and one day at the other. This makes my continuity for patients really, really quite minimal." (FG#4, NP22)

In addition, large 'busy' patient caseloads were implicated in obstructing the support patients needed as a consequence of juggling workloads to fit the time allocated, as indicated below:

"Sometimes you feel you just can't get to know the patient you know get close, cos you're so busy. Like last week, I'm running late to go out on home visits, which makes me late for that one and the next and the next. You can't get up and leave; you can't say you need to go somewhere else. I can never give times, it will am or pm. And that's as much as I can say to patients for home visits because of the fact you just don't know what you're going to encounter when you go to see that patient. It could be absolutely fine and then the next one you could go and see and sit there for an hour and a half because they're distressed about something. You just don't know what you're going to come across." (FG#2, NP19)

Lack of resources imposed within the employing NHS Trusts of the nurses was also seen as a contributing factor to accommodating hurdles for good patient care. Stoma care service provision varied greatly among them as some were able to offer "as many home visits as the patient needed" (FG#3, NP14), whilst others "no home visits at all" (FG#5, NP27). Home

visits were seen as opportunities to discuss any problems patients were having in the privacy of their own home and for those not offering follow-up care in the community this inferred it did not allow them to explore patients' problems in any great depth, as illustrated:

"We do no home visits at all, that's covered by the community based stoma nurse. I think it takes time to get to know your patients well and when I don't get access to a clinical room at their appointment it means I can't talk to them properly. So I feel awkward not being able to start conversations that might be sensitive and I expect the patient feels awkward too." (FG#5, NP27)

These changes in clinical practice and organisational constraints were demonstrated by feelings of frustration, inferring that the nurse-patient relationship was not as it once was. The nurses were seen to explore creative ways in which to improve their communication and information giving with patients so that they could be independent in the care of their stoma. Connecting and communicating with patients was seen as an important aspect of their role. Building a good nurse-patient relationship was reported to begin in the early pre-operative stages where information giving and good communication were imperative and linked to the following theme.

7.5.4 Communication skills

Effective communication was highlighted within all the focus groups but only considered in any depth in four out of the seven focus group discussions. Acknowledgement was given to the need to communicate differently depending on the patients' situation; in response to the vignettes a narrative from FG#7 outlined this:

“You would talk differently to the first scenario than you would the 2nd, not only because one is a young man and the other an elderly lady, but you need to listen to their individual needs. This then reflects on how you talk back so that you say stuff in the way they understand.” (Theme 3, vignettes 1 and 2, FG#7, NP35)

Emphasis was placed on competent communication skills being just as important as competent knowledge. The nurses acknowledged that listening closely was critical to understanding the patients’ problems. In addition, the need to ask the right question at the right time was also considered; this was highlighted in FG#2,

“We often feed off what patients are giving you. So as long as you’re asking the right questions to get the information back, you go with what the patient needs.” (FG#2, NP9)

Communication skills included active listening (FG#1), picking up on cues (FG#7) and use of appropriate language/terminology (FG#5). Picking up on cues was seen as an essential skill in easing problem solving in what might be a difficult situation, as this nurse described:

“And that other 95% just takes experience of working with the patients and picking up the cues of what people are saying is a problem. And then once you realise that there is a general issue around sexual relationships and body image, you feel more confident to perhaps say to somebody who isn’t more open about that, ‘Are there any other problems that you’re experiencing other than just, you know, sticking a bag on your belly and the practical issues of stoma care.’ (FG#5, NP27)

Cues were mainly viewed as an aspect of actively listening to the patients’ conversations, as illustrated:

“Yes you’ve got to listen for the cues. And if you miss the cue then you know, you sometimes end up just playing daft. I sometimes say, ‘I’m sorry, I don’t quite understand where you’re going can you explain it?’ And sometimes in that, it unravels what they’re really talking about, you know, rather than going round the houses.” (FG#7, NP35)

“Yes it’s kind of listening for the cues isn’t it? And if the cue is, you know, ‘My daughter and her feelings,’ it’s kind of, you can flip that round and say, you know, ‘Why are you particularly worried about how she would feel?’ you know, ‘How about how you feel?’” (Theme 4, vignette 1, FG#2, NP11)

“Listening to them and waiting for that little opening that you can then explore it more and giving them the opportunity to talk about what’s concerning them.” (FG#5, NP27)

Other nurses highlighted that observing patients’ non-verbal cues was just as important as listening to them, stating:

“Quite often if you know the patient, you’ve had a relationship with them, you are kind of used to the non-verbal’s, so you can just tell when they walk in, by their body language, whether they’re upset or not. If it’s a new patient and you’ve never met them before then it’s a bit more difficult.” (FG#2, NP12)

“It’s a combination, I think, of body language, it’s the tiny little clues that you pick up, you know, it’s maybe the lack of eye contact or maybe the way people look down and try to avoid you.” (FG#7, 34)

There was an awareness to control the amount of information giving as there was no wish to overload patients with unnecessary information, as one nurse informed her group discussion by sharing an experience from her practice:

“I’m always careful now, you know, how much information I give to patients. I saw this gentleman after he’d seen the colo-rectal nurse and been pre-assessment. We spoke about his surgery and what it was all likely to mean and placed on the desk, all the leaflets to support what we had spoken about but he didn’t take them. When it came to him leaving I said don’t forget these, picking up the leaflets, he replied, opening his jacket, ‘no room, love, I’m all brochured-out’. His pocket was stuffed with information from everyone he’d seen that day. Thing is I knew what I’d attempted to give him was probably more relevant than the rest.” (FG#1, NP5)

The skill of pacing information giving was also seen as important, as highlighted:

“I try and drip-feed my patients when it’s appropriate, you can’t bombard them, some are in shock with their diagnosis let alone thinking about living with a stoma.” (FG#7, NP35)

“You can get all the information, but you can’t get too close to them and things, because there’s barriers that sometimes you just can’t break. And you have to accept that some people don’t want to tell their life story to you. And we have to respect that. And sometimes, as nurses, we do expect them to just open the doors and we can solve everything and help them and as today, with the scenarios, it’s quite clear sometimes that you can’t – people have agendas don’t they, and some see you as - you’ve come in, you’re the nurse.” (FG#6, NP28)

An assumption to presume information had been given to patients was also recognised, as in this example:

“Patients don’t come in boxes, they’re kinda spread out into lots of little boxes. There’s a temptation to assume that others have referred on or spoken to the patient in detail about what is happening to them – sometimes it’s like you play the role of gatekeeper.” (FG#4, NP19)

The nurses referred to themselves as being pivotal in a patient’s journey to recovery in providing effective communication between the patient and other members of the multi-professional team, as one nurse stated:

“I say to patients, ‘you must tell us how you’re feeling, cos your recovery is, well it’s like a mountain range, you’re going to hit the top and think wow this is great and then two days later you have an off day and you think, what have I done wrong?’ And it might not be anything that they’ve done wrong. It just may be physically that they’re tired or something else has come into play in their life, you know. Something that’s affected their stoma.” (FG#2, NP8)

Being open and honest in communications with patients related to the language being used. The nurses highlighted the importance of using language that was realistic and in a manner patients would understand. There was a sense that using subtle language was more

acceptable to facilitate the patients' adaptation to the stoma; *'soften the blow'*. A patient from phase 1 described how she found this type of language reassuring:

The nurse said 'it was a nice one (stoma)', neat I think she said, so I was slightly reassured". (PT#4, female, 66 years, Diverticular disease)

This might suggest a subtle type of language is common to the specialty of stoma care. It could be surmised the sentiments behind this are empathetic and the specialist nurse is attempting to comfort the patient through what was considered a *"traumatic experience"* (PT#4, female, 66 years, Diverticular disease). Interestingly, patients in phase 1 of this study expressed a wish for the specialist stoma care nurse not to minimise the impact of the stoma as a way of enabling them to cope. This was seen by the patient participants as a short term coping strategy and did not really allow them to dislike the stoma if they wanted to.

The nurses shared the view that good communication was fundamental to good practice. Their narratives suggest advanced communication skills needed to be upheld. There was an awareness of the need to control the information exerted, use language appropriate for and understood by the patient and pick up on verbal and non-verbal cues. Some nurses admitted to patient interactions where communication was not straightforward; alluding to them entering uncertain ground.

7.5.5 Uncertain ground

Uncertain ground characterised the nurses' feelings to addressing sensitive, complex and difficult conversations. This theme refers to the uncertainty of revealing issues that they

would not feel comfortable addressing whilst ensuring such difficult conversations with the patients were had. This was attributed to a fear of not knowing what would be uncovered (FG#5), concern for misreading patients cues (FG#3) and guilt if patients were left feeling as if their problem remained unresolved (FG#4). Recognition was made to the types of issues they were likely to encounter:

“We deal with complex cases, patients with IBD have chronic issues that are long term and cancer patients are dealing with worries about death and dying. We have patients who take longer to adapt to having a stoma than others, we have those with relationship issues, we have those with sexual function issues, it’s varied and complex.” (FG#3, NP14)

The nurses identified a range of challenges around deciding whether to open conversations with patients or not. They felt the need to ensure that patients had the opportunity to engage in difficult conversations. The need to be sensitive with a patient’s wishes to talk was seemingly guided by that patient’s cues. This was not seen as a passive approach but more about being mindful of the wishes of individual patients through their cues and therefore being prepared to facilitate the conversation, when they perceived the patient was ready, as shown:

“You’re talking to them about very uncomfortable things such as bodily functions, poo, wee, you know, all these things – the fact that the procedure can be quite mutilating and affect how they feel about themselves and their sexual function. You’ve got to get the timing right and listen to when it is right for them to open up and have that conversation cos they associate us as people who deal with very difficult things.” (FG#4, NP23)

The nurses shared the view that they would all at some point need to deal with difficult conversations:

“Especially as they’ve probably come to you for that reason, because they can’t talk to their loved ones about it. So they all, I think they trust in us in dealing with emotions, because we’re nurses at the end of the day. So they probably come in not knowing whether they will open up to us and probably sit in that waiting room going through a little role-play in their head of, ‘Will she ask me about sex? Will she ask me about my relationship?’ And they’ll come in and if you don’t say that, they probably, more often than not, will go away not really challenging it.” (FG#4, NP19)

Some nurses reported that some patients found it extremely difficult to openly discuss and share their concerns. This was confounded by their difficulty in talking about their stoma and the feelings they associated with it. The nurses spoke of how they would start a conversation only to find the patient was not willing to engage with them:

“You can start a conversation and try and find out how they are feeling about the stoma, some talk freely and some don’t. You’ve just got to respect that.” (FG#3, NP14)

“Yes, it’s very dis-consoling though when you go into a patient and you want to share so much with them to actually improve their quality of life and it is just a brick wall cos you know that they aren’t listening to what you have to say.” (FG#6, NP27)

Nurses also spoke of how they used their specialist skills to tease information out of some patients in order to assist their clinical judgement; sometimes this meant treading uncertain ground:

“I knew what she wanted to talk about, and I didn’t really want to go there, cos I was worried I wouldn’t have the right answers and then she’d lose my trust. I think we were both feeling awkward and uncomfortable. I know I was. Still I carried on, listened to her, tried to read her cues and gradually we unravelled the problem.” (FG#3, NP13)

The fear of *'getting it wrong'* (FG#3) was apparent, particularly misreading cues and making mistakes. Fearing the outcome of a mistake was expressed as being unhelpful to the recovery of the patient and their relationship with them:

"If I'd taken the discussion any further it might have had a detrimental effect on the patients' recovery and our relationship, so if they don't want to go there then I don't." (FG#4, NP20)

NP17: *"sometimes you have to delve a bit deeper....."*,

NP15: *"but it's about being brave enough to dig a bit deeper, cos sometimes you just don't know what you're going to uncover"*,

NP17: *"That's what I mean and not just skim the surface because you're not helping them, I don't think, sometimes, because you need to dig a little bit deeper"*,

NP13: *"yeah, sometimes you do this with trepidation cos you just don't know what you're gonna uncover..... patients tell you all sorts, sometimes nothing to do with their stoma and you've just gotta be prepared."* (FG#3)

"It's too uncomfortable, it's too near the bone, it's too upsetting, it's too near to your personal experiences maybe. Maybe the barriers that you don't really understand yourself that you have. It's just trying to look at those and delve maybe a little bit deeper. There's all sorts of reasons why you might not, you might just not be on the ball." (FG#5, NP26)

The importance of knowing the patient and developing a close nurse-patient relationship has been previously presented. The risk of opening up a conversation that might harm this relationship was apparent. This was compounded by potential time constraints. The ideal time allocated to patients attending a nurse-led clinic was considered by FG#5. Reporting *"twenty minute slots at clinic"* (FG#5, NP26), was felt to make conversations difficult to initiate; being brief and to the point was not always possible, as illustrated:

"Conversations can be difficult especially if you open up a can of worms, because once you've done that you've got to follow it through, you can't just say 'oh sorry that's your time up, I haven't got time today, can you make another appointment and come back another day'. Particularly if it's sensitive, you know, and want to talk about their problems with sex or going through a difficult relationship, they've

plucked up the courage to talk to you and you need to pluck up the courage to talk to them too and be able to see it through.” (FG#5, NP25)

This narrative also implied such conversations took risk and courage due to the uncertain nature of what might be uncovered. The nurses demonstrated an appreciation of the fact that a key aspect of their role was to address sensitive, complex and difficult conversations. Their specialist knowledge and skills seemingly guided them to support the wishes of patients.

7.6 Summary

The purpose of phase 2 of this study was to explore the complexities of navigating specialist knowledge and skills by the stoma care nurse to facilitate patients need to adaptation to stoma surgery. The findings presented highlight competent knowledge, skills, expertise and communication as essential to specialist practice. Attention was also drawn to the obstacles and uncertainties faced within specialist practice and how clinical supervision was used to explore strategies for problem-solving as well as self-development.

The overarching aim of this study was to identify the transmission of knowledge and skills of specialist nursing practice. In order to achieve this, further examination of the phase two data was required through a different lens prompting a third stage to the analytical process.

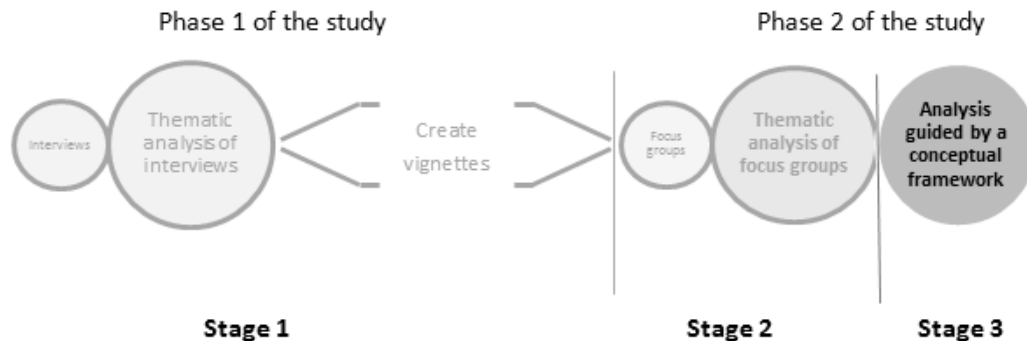
A third stage to the analysis process was considered to distil the pedagogy and a theoretical framework for the analysis was chosen (See Figure 7.5). The concept used was the

emotional intelligence theoretical framework of Mayer and Salovey (1997) as outlined in Chapter 6. These findings are now presented.

7.7 Analysis of Phase 2 using a theoretical framework

The branches and characteristics (See Table 6.7) of the emotional intelligence theoretical framework (Mayer and Salovey, 1997) guided stage 3 of the analytical process (See Figure 7.6). The branches and characteristics of the framework were used solely to guide this third stage analysis.

Figure 7.6 - Stage 3 of the analysis process



Focus group dialogues were examined once more to ascertain what features of emotional intelligence would assist in identifying pedagogical components for specialist practice. The focus group narratives were colour-coded to represent the differing branches, thus assisting the analysis (See Table 7.4). Words, expressions, phrases and conversations from the focus

Table 7.4 – Example of analysis (Extract from FG#2)

<p>Nurse participant narrative (<i>line from narrative</i>) (Facilitator (F), Nurse Participant number(NP7-12))</p> <p>Line from transcript</p>	<p>Narrative interpretation</p>	<p>Potential Meaning</p>	<p>Branch Perceiving emotions (PE) Facilitating emotions (FE) Understanding emotions (UE) Managing emotions (ME)</p>
<p>327 NP7: This chap I've got in hospital at the moment, he's a retired policeman. Pre-op he asked all the right 328 questions, we went through them all, I saw him 2 or 3 times before his surgery, and yes, he'd tried the 329 practice pack, put a bag on and everything felt fine. My gut feeling was brilliant, good job done 330 easy recovery and then off we go. Post-op, I can't believe how he is 'Let's try removing your bag today, 331 so I takes off the drain bag and 'What are you doing? he says. He just looked so befuddled and in such a 332 mess. He just can't get his head into gear of what's going on. It totally surprised me about him 333 NP9: I bet it's shock and in three months' time he'll probably be a different person..... flying 335 NP7: Oh yes I know, he will, yes but it's all about how he's feeling inside at this point. 336 NP8: It all depends on their ability to cope, because everyone copes differently, it could be like we said before, 337 ten years down the line it can suddenly, everything fall in on them, and it can stem from anxieties that 338 they've suppressed because they've just got on with things. 339 NP10: I think a lot of the times at pre-op, you show the patient a picture of a stoma and it's a lovely, pink, healthy 340 little blob. Then they wake up from surgery and they look down and they see this horrible brown, dark 342 bruised thing that's producing poo and trumping. They go, 'Ugh, it didn't look like that in the book. And as 343 time goes by then realise, and there's a sense of 'Ah, I see what you mean. But at the time you have to 344 soften the blow. 345 NP8: You should avoid those post-op pictures in the book, they need to know the truth, even if it seems unreal, 346 those pictures don't help them face reality. 347 NP9: Yeah, it's like those pictures have been air-brushed! 348 NP10: It's only yucky for a short time, I think it's positive to see how it will look eventually 349 NP11: It always looks like a really nice pink healthy stoma in the books. You should say, yes it might look like that 350 but in a few months' time. Patient's need to trust you, books only help a little it's how you and others eact, 351 you know they look at your expressions, watching your you know, you might grimace at the smell but it's 352 so important not to cos then they'll really think 'Ugh, I'm never gonna cope with this horrible thing'. You 353 have to be so careful. They'll accept eventually, it might take longer, those initial stages are 354 important. 355 NP10: It's all part of the healing process, I guess</p>	<p><i>Retired Policeman undergoing stoma formation, appeared to demonstrate an understanding of the surgery pre- operatively but completely taken aback post- operatively, to the nurse's surprise.</i></p>	<p>Patients previous experience of stressful situations might have been suppressed and this episode has triggered this 'befuddledness'</p> <p>Assumptions</p> <p>Honesty</p> <p>Body language</p>	<p>PE: CNS recognised that patient not coping in the post-operative phase and that there were many conversations to have in the future.</p> <p>FE: CNS surprised at patient's reaction to the stoma. Assumptions made regards occupation Language of stoma description 'False' information in order to improve the situation. Care with facial expressions</p> <p>UE: CNS acknowledges that everyone copes differently.</p> <p>ME: Avoids showing post- op pictures of the stoma</p>

group narratives corresponding to the branches and characteristics of the chosen emotional intelligence theoretical framework were identified and grouped together.

Five essential elements of specialist nursing practice were identified; the influence of emotions on critical thinking and decision-making, the use of empathetic and intuitive skills in clinical judgements, the ability to balance true self alongside professional self, the need to foster cognitive activity, good communication and creativity and preserving a conscious awareness of self to develop personal growth. The focus groups represented a group of specialist nurses with a comprehensive array of knowledge and skills as well as diverse experiences both personally and professionally. These findings are presented using the branches of emotional intelligence as sub-headings to illustrate the characteristics within each branch (Mayer and Salovey, 1997).

Table 6.7 - *Branches and characteristics of Emotional Intelligence theoretical framework (Mayer and Salovey, 1997)*

Branch 1	Branch 2	Branch 3	Branch 4
Perceiving emotions (PE) Characteristics <ul style="list-style-type: none"> •Self-awareness •Emotional self-awareness •Accurate self-assessment •Self-confidence •Gauging the mood •Tuning into your sense 	Facilitating thought with emotions (FE) Characteristics <ul style="list-style-type: none"> •Emotional self-control •Cognitive process – comprehension of language, learning, reasoning, problem-solving, decision-making •Intuition •Initiative •Adaptability •Conscientiousness •Trustworthiness 	Understanding emotions (UE) Characteristics <ul style="list-style-type: none"> •Empathy •Recognition •Clinical reasoning •Critical thinking •Clinical judgment 	Managing emotions (ME) Characteristics <ul style="list-style-type: none"> •Communication •Working as a team – working towards similar goals •Nurturing relationships – building rapport •Change agent •Leadership •Developing self and others – personal growth •Influences •Conflicts

7.7.1 The influence of emotions on critical thinking and decision-making

The nurses shared the view that clinical decision making was the ability to think, understand and act systematically to solve problems. Describing how their emotions influenced their critical thinking allowed them to re-evaluate some clinical situations. This complex process involves recognition, clinical reasoning, critical thinking, clinical judgement and reflective practice, all of which reflect the ability to perceive, facilitate and understand emotions as outlined in Mayer and Salovey's (1997) emotional intelligence theoretical framework (See Table 6.7).

Emotions such as fear, anger, sadness, anxiety and frustration were all demonstrated and in some instances were described as sub-consciously controlling patient care, leading to the misinterpretation of some clinical judgements. Being effective was seemingly dependent on the nurse's ability to think and feel whilst integrating their critical thinking with their emotional ability. The nurses considered how they understood their own emotional self-awareness and perceptions in order to understand the stoma care needs of patients:

"I always say that psychology and physical care are wrapped around each other. The heart isn't the emotional organ of the body, the bowel is! When we're in love, we've got diarrhoea, when we're out of love, we've got diarrhoea. Patient comes in following emergency stoma surgery and they feel totally out of control; the ileostomy is going crackers because they're that chewed up, they're not eating, they're not feeling right, they're unhappy, 'My God what's going to happen?' Getting a physical and psychological balance is crucial. And that's why, when you go on wards and they're leaking, you want to stop them leaking because patients think, 'My God is this my lot? I've got to have this permanent stoma, is this how I'm going to be?' So leaking on the ward has to stop, do you know what I mean?" (FG#1, NP4)

This narrative offers a heartfelt insight into the nurse's perception and understanding of the patient's experience. Demonstrating such empathy, compassion and understanding captures this nurse's ability to identify much of how the patients were feeling in phase 1 of this study. Here it is used to recognise how emotions become wrapped up in psychological aspects of care, a role that the nurses determined as less visible but intrinsically important.

The need to integrate their thinking and feeling by using both their emotional and analytical awareness simultaneously was seen to facilitate their clinical reasoning. Moods and emotions were viewed as playing a central role in influencing decision-making processes. Gauging situations clearly affected critical thinking and clinical judgement, as these narratives clearly captured, resulting in the nurses questioning their clinical decision-making:

"I think the thing is, I was talking – it's funny, before I even came, today, I was talking to my colleague about a patient who's rung me, totally out of the blue, I've not had contact in ages, she's now terminal and end of life kind of stages, she's not got very long left at all, bless her. And she's young and I've been with her right through all of her cancer and stoma journey. She's not got any stoma problems, but rang me to ask me to go round. And I asked myself 'How did I feel about this, you know, I just thought how does this make me feel and what should I do'. I had to weigh what I knew about her and the situation. So I went, we sat talking for over an hour, we didn't even talk about her stoma and I left. I came away confused, 'what did I go there for', I thought. I started to feel like I wasn't sure why I went and why she called me, but I had a gut feeling to go. I don't regret going but think my emotional attachment to this women overshadowed my clinical thinking." (FG#3, NP15)

"We used to have a lady that kept coming back and would turn up at our clinic dead on five o'clock as we were all walking out! It used to be a running joke, and I used to think 'did she do it deliberately', you know, 'was she testing us as specialist nurses'. She was constantly challenging. The situation made us feel very frustrated and angry, we even tried to pre-empt her visits with a phone call but she still came; same time. So we'd all take it in turns to stay for an hour and counsel her and go through the process. She's not with us any more, bless her, but, you know, that's what, we

realised, that's what it was all about. We couldn't understand why she was always banging on. It was like she sat in the car and just waited, because it was as we were literally coming out of the building and she'd jump out of her car and expect us to see her. We spoke about the situation afterwards as a team and I think we all felt we were wrapped up in our frustrations that nothing seemed to help, that we probably missed the support she actually was seeking. That realisation was hard." (FG#7, NP34)

"I've got an elderly lady at the moment who calls me a lot. I'm sure she makes things up, she makes up that she's got diarrhoea or that she's got a painful stoma. Every time I go round and see her, there's absolutely no problems whatsoever. Not that they're big problems, but I think to myself 'what if I didn't go, what then, what might happen?' Then I feel guilty but it's a bit like the boy who cried wolf, you know. So my heart is telling me she's asking for help and my head is saying, I need to encourage her to be independent. Getting that balance right, sometimes it's a hard judgement call." (FG#5, NP25)

These narratives describe how the nurses felt in clinical situations from their own practice areas. They demonstrate how such challenging emotions influenced their clinical judgements and drove their behaviours. Their ability to be effective was dependent on the ability to both think and feel, and integrate critical thinking abilities with emotional abilities. The nurses were effective in identifying their emotional abilities but questioned their integration with clinical reasoning. Tuning into the patients emotions, positive and negative, allowed the nurse participants to assess the situation and focus on what was important for the patient at that moment in time.

Such behaviour suggests nurses' appreciation of the depth, diversity and complexity of emotions and how these might affect their own behaviour and that of others. Gauging the mood reflected on the nurse's own '*emotional commitment*' (FG#5, NP26)) to their clinical judgement and decision-making. Some nurses described how easily, if the mood was not gauged, they could assume and misinterpret some clinical situations, possibly influencing their judgement:

“There’s a risk we can all make assumptions, because of the patients age, it might change how you judge them and deal with their problem.” (Theme 5, vignette 1, FG#4, NP18)

“The temptation is to assume they (the patient) will be OK and then you miss something, judging it right is important.” (FG#7, NP35)

“You could easily but can’t just assume what’s important to people; children, husband, dog even, you need to know what’s important to them as a person so that you can support them. Its fact not fiction that should help you decide.” (Theme 4, vignette 2, FG#2, NP12)

“It’s only natural to assume, but since I’ve been a stoma care nurse I’ve learnt to listen and gauge how they (the patient) is feeling and then support them as needed, cos otherwise you risk prolonging their recovery.” (FG#5, NP27)

There was an appreciation by the nurses of gauging the mood first, to enable them to assess and establish the type of situation they were entering. Tuning into their own emotions and those of their patients meant the nurses could focus on what was important for individual patients. The ability to understand the true meaning of a situation, particularly when it was not obvious or expected, was highlighted as being dependent not only on what is said but also on what is not said. The nurses described non-verbal cues as a supplement to listening to what patients or their relatives said. A view shared by the nurses was that words alone did not always relay the entire story. This was illustrated in stage 2 of the analysis (FG#7, FG#2). Both verbal and non-verbal communication provided the specialist stoma care nurses with the information and knowledge they required to deal with the complex issues brought about by stoma surgery.

Noticing disparity between verbal and non-verbal communications was seen as crucial; needing to ‘*read between the lines*’ (FG#7), meant that situations were not always accepted at face value. This was a skill the specialist stoma care nurses indicated they required to

assist their clinical reasoning when dealing with the complex issues brought about by stoma surgery, as illustrated:

“You know it wasn’t what was said it was more what he didn’t say, you know, the way he sat in front of me, his hesitancy, I sensed there was more to how he was feeling, so I probed a bit more and sure enough, we got to the root of what was troubling him.” (FG#7, NP39)

The nurses recognised that patients needed their time to listen and understand their current issues and not always to have solutions. These findings have already been illustrated (stage 2) as to how the nurses felt not only a thrill to ‘fix all’ (FG#7, NP38) as it made them feel valued and needed, but with it came much pressure and stress to deliver and maintain their specialist skills, particularly if all other avenues of stoma care management had been sought. This challenge was highlighted in FG#7, stressing the importance of critical thinking and judgement and subsequent actions. Understanding these emotions enabled the specialist nurses to intervene more effectively. Once a nurse correctly identifies, understands and uses an emotion to facilitate reasoning there is a greater ability to manage clinical situations more productively. This indicates a need to increase the feeling of control and emotional competence, an ability Mayer and Salovey (1997) believe once harnessed can make a key difference to critical thinking and clinical decision-making.

7.7.2 The use of empathetic and intuitive skills in clinical judgements

A core feature within the narratives was the nurses’ ability to demonstrate skills of empathy and intuition. The ability to know, understand and connect with patients without reasoning was described by the nurses as an influencing factor enabling them to problem-solve in an empathetic manner. A view shared by the nurse participants was that this is a skill specialist

nurses need to foster. The nurses' narratives suggested, as expertise and experience increased, skills of intuition interwove and enhanced the ability to demonstrate empathy. This in turn intuitively led to a therapeutic intimacy between the patient with a stoma and the specialist nurse as the nurse is perceived to facilitate and understand emotions (Mayer and Salovey, 1997), for example,

"Intuitively I visited the patient, at the time I remember thinking 'what on earth did I go there for?', when I arrived I knew she was dying, so sad, we've known each other for a long time, I was so glad she called." (NP6, FG#3)

Here the nurse's ability to both think and feel and to integrate critical-thinking abilities with emotional abilities reflect a decision-making process which appeared largely based on an integration of emotions and intuition.

Nursing skills aiding the development of the therapeutic relationship were considered during the focus group discussions of which some have already been stated. The nurses felt an expression of compassion was to possess an understanding and positive feeling towards the patients and their families and was seen as an essential feature of the therapeutic relationship they had with the patients living with a stoma under their care. A view shared, was that specialist nurses need to be in the position to re-assure patients, offer sympathy, consideration, demonstrate sensitivity, empathy and offer emotional support. The ability to demonstrate empathy was prominent, as captured by this nurse:

"Empathy is definitely a skill we need to have. The empathy you have for your patient's situation doesn't trigger some sort of immediate response where you can jump in, save the day and get loads of credit for it, but it's about helping that person adapt to living with a stoma and I suppose, become better at being themselves. So, to the chap, you might say, 'it sounds like you've been thinking about your family and how your stoma is

affecting them as well as yourself', and this might open up a conversation about how he feels this (stoma) has affected his family, which is obviously worrying him." (Theme 4, vignette 1, FG#2, NP11)

Knowing and connecting with patients as well as experiences in life was seen to facilitate empathy as an evolving skill for specialist practice, as described:

"I think I've always connected to my patients and shown them empathy towards their situation but since becoming a mum, I feel I'm a much better nurse. I'm more in tune, I've got more empathy and sympathy for other people than before I was a mum, definitely. It's like the experience has given you a whole new perspective." (FG#3, NP15)

"Knowing you understand your patient means you can start to give them back their independence. I think this is really important. Sometimes they are scared, everything's new and they don't want to be responsible for their stoma. But knowing and understanding them means you can provide them with the right skills to cope, you know, so they stay motivated and are well informed, and you can then support them with the right choices for their future." (FG#7, NP37)

There was certainly a sense that the patient was central to the care given, as captured by this nurse:

"It's so varied, what we do, you know, each patient you encounter is so different, in the morning I could be seeing, a 26 week old gestation baby that I can put in my hands, and then later in the day go and see an octogenarian. Individualised care can be complex but so important, you've got to be ready for the acute, the palliative, the curative and whatever and be flexible to adapt to the needs of that patient." (FG#6, NP32)

Confirmation of how differently patients cope following stoma surgery and the profound effect of living with a stoma was illustrated by the patient narratives in stage 1 of the analysis. These findings revealed feelings of shock and numbness as participants came to terms with the consequences of stoma surgery. The nurses revealed an understanding of their relationship with stoma patients describing it as 'intimate' (FG#3, FG#7), 'trusting' (FG#7), 'therapeutic' (FG#1) and 'close' (FG#2, FG#3). This was primarily due to being a part

a 'patient's entire journey' (FG#3, NP17). According to the nurses this relationship was built upon understanding the needs of and learning from patients, supporting them through times of particular difficulty.

The meaning of this relationship emerged through the narratives of the nurse participants. They spoke of encounters that were rewarding and brought them feelings of personal joy and achievement to professional mindfulness:

"It's so rewarding seeing the patients adapt, knowing you've been a part of their journey, I know, it's team work. They are so anxious at first but you have the skills to ease their anxieties, it helps seeing them in hospital and at home." (FG#7, NP38)

"We had a patient return to the clinic last week, he was unrecognisable. He looked so well. He said he was eating well and was now back to his normal weight, his skin was clear, he just looked great, he was back at work, new girlfriend, he's done so well. It is so rewarding to know you've been a part of that patients' entire journey, for him, and I guess cos his stoma is permanent we will continue to be a part of his life – well as he needs us." (FG#3, NP17)

"Sometimes I cover the hospital and the community, you know, for holidays, and you end up giving patients a whistle stop visit, you feel guilty for not giving them the time they deserve and it just causes everyone unnecessary stress." (FG#1, NP4)

"You've got a visit in the community as well, and you're giving the patients just whistle stop visit and you know for a fact that you're doing the main bit, but you're not giving the time that they deserve. And you go home guilty and, you know, feeling like you haven't done your job right." (FG#4, NP22)

Relationships were developed through openness and honesty with patients. The nurses felt that they needed to be honest with patients and the more familiar they became with patients, the easier it was to be open. However, some nurses found it uncomfortable to be honest with patients as they feared their reaction, as illustrated:

“And sometimes it’s hard being honest with them (patient) but I think you need to be, because the reaction you get from them is very difficult and we might feel uncomfortable with future discussions with them (patient).” (FG#1, NP3)

But being truthful to patients was deemed a fundamental aspect of the specialist role as described during discussions relating to theme 1, vignette 1 in FG#6, when they stated:

*NP29: “I think the first lady, the lady with Crohn’s, she’s the most difficult”.
NP32: “I know, but you would be asking them why she feels it’s ruined her life, because having Crohn’s, she’s obviously dealing with an inflammatory process, probably been very unwell, but, you know, she’s got a business and she’s obviously a very active lady. You know it is about trying to, you know, is she more in control, you know, whereas before was she ill, really unwell, looking for toilets all the time, you know, trying to put a support, a positive spin on it, but really the first thing would be, why does she feel it has ruined her life. And yes that is a, you know, ‘I only agreed to have it done as a temporary stoma.’ Well she’s got a loop so it could possibly be that it is temporary. You know, so you need to know the reasons why and why they did that. Was that to relieve the back passage because that’s where the Crohn’s is, or is it – do you know what I mean? To know the patient, to then support them truthfully. And I think as stoma nurses, we are the truth, we do tell them how it is, because that’s what we’ve got to work with really.” (FG#6)*

The nurses considered other healthcare colleagues to be not so truthful and honest, leading them to feel they were providing conflicting information to patients, as illustrated:

“They (the doctors) give a timescale of weeks (stoma reversal), at the time it sounds a lot to the patient, made even worse when you know it’s more likely to be months or even a year and so. So you’re the one, you’ve got to go and tell the patient that. You say, ‘look I need to be honest with you’, this is what could be the reality. And that’s hard, sometimes it’s hard being honest with them, but I think you need to be. However the reaction you get from them (the patient) is very difficult. They look at you disbelievingly because the consultant said ‘blah, blah, blah’ and I think for them to have conflicting information, well that can be difficult too.” (FG#2, NP10)

A view shared by all the nurses was that intuition was seen as an integral part of problem-solving stoma care related issues. They spoke of having a “*gut feeling*” (FG#1), ‘*gut instinct*’ (FG#4) and “*automatically know*” (FG#5) what was going on in the situation, as if it signalled a certain direction for them to follow, as described:

“Intuition, I think it’s a combination of body language and those tiny little clues that you pick up, you know, it’s maybe the lack of eye contact or maybe the way people look down or try to avoid conversations, you just get a sense of what’s going on.”
(FG#4, NP21)

“I was visiting this patient and knew I had another patient in the same road, who I hadn’t seen for a while. I’d got some spare time, so I popped into see her. I have no idea why or what made me go, gut feeling I guess, but I’m so glad I did. She was not coping at all, her bags were leaking and she said she didn’t want to trouble us.”
(FG#1, NP6)

The inference here is that intuition develops with experience. The nurses spoke of how their communication skills had developed with experience allowing them to sense and “*pick up on cues*” (FG#7) or having experienced a similar situation then “*you’d just know*” (FG#1), as illustrated:

“In terms of gut instinct, you feed off what the patients are giving to you. So long as you’re asking the right questions to get the information back, you go with what the patient needs, experience has taught me that.” (FG#2, NP9)

The nurses acknowledged the complexities of information giving to patients, emphasising the need for patients to receive ‘*the right information, at the right time for them*’ (FG#2, NP9) in a manner they could understand. The importance of using appropriate language and information giving for a patient to comprehend has already been presented in stage 2 of the analysis. Understanding a patient’s worries and concerns helped create a relationship with

the patient characterised by mutual confidence and trust. An illustration of this was during a conversation in FG#4 when discussing theme 3, vignette 1:

NP18: "Well he's, the boy – his language well he uses very disjointed sentences, finds it hard to articulate properly what he wants, as though he's trying to say something, but he can't quite put it into words properly,"

NP24: "Yes, you really have to listen and pick up on the slightest cue to grasp what they really want",

NP22: "He wants his privacy"

NP24: "I know, but it sounds like he's alone at the university and I think he's avoiding the issue, 'I tend to just deal with it' he says,"

NP18: "But if he can't articulate what he wants, you should try and connect with him, he might be anxious or blocking things out, he certainly seems like he doesn't want to talk about it." (FG#4)

Integrating their emotional, personal and social awareness seemed to assist the nurses with their ability to solve problems and make clear clinical decisions as Mayer and Salovey (1997) recognised. The nurses expressed the importance of cognitive processes and social skills for stoma care nursing as the ability to empathise and to communicate. Possessing such skills enabled the nurses to deal with problem-solving situations in a positive and purposeful manner.

7.7.3 The ability to balance true self alongside professional self

The nurses spoke of their inevitable close relationship with patients. They spoke of how it was a privilege to be a part of a patient's journey as they adapted to living with a stoma. As their nurse-patient relationship developed the nurse participants acknowledged that they, the nurse and the patient would undoubtedly share unique aspects of self.

Two aspects of self were identified; the personal self (FG#4) and the professional self (FG#6) as the following two narratives illustrate:

NP18: *"it's only natural that you give a little of yourself to the patient",*
NP24: *"yes, it lets them know you understand how they are feeling",*
NP19: *"yes, cos then you show them your compassion and empathy towards their situation",*
NP24: *"... the patient's",*
NP20: *"I think, for me, it's a combination of my knowledge, experience and me, who I am and the way I am and I guess how I portray myself",*
NP21: *"yeah and also what you tell them about yourself." (FG#4)*

And

NP28: *"showing you are professional means that the patient, they can trust you,"*
NP30: *"yes, being honest and professional",*
NP29: *"I think it's something about showing yourself as you think the patient imagines us to be.....",*
NP28: *"yes, so we come across as efficient, competent and professional",*
NP29: *".....Well, yeah, but we can protect ourselves a bit, can't we?"(FG#6)*

In such a close relationship the nurses described an unavoidable risk of the blurring of boundaries. Discussions took place around giving of oneself and the boundaries of specialist practice. They saw some boundaries as clear cut whilst others were more opaque and required a *"good judgment call"* (FG#6, NP29) to make a conscious clinical decision. Building a close nurse-patient relationship whilst maintaining professional boundaries was seen as challenging during sensitive and intimate moments with their patients. Whilst the nurses could see the value of investing in the therapeutic relationship, some questioned the implications of their actions, as captured by these two nurses:

"Sometimes the patient has given me a kiss, when they have left and I've often thought, 'Is that professional'? – then I think no, she's an elderly lady and if she wants a 'kiss and cuddle' then I think that's acceptable – it's an crucial time for them and I wouldn't want her to feel rejected." (FG#2, NP10)

"For the last two years we've had mobile phones for our patients and we give them our contact numbers; like the others in my team, my phone doesn't get switched off. I've

had little arguments with my partner because, he'll say 'You're not in work now, turn it off,' and I'll say, 'No it will stay on.' I have thought about whether it's a good thing or not but I'd rather speak to someone for three or five minutes and give them reassurance than them be waiting until the following day for them then to be really upset.”(FG#3, NP17)

Others spoke of a need to create a balance as a means of preserving self. They described how they had come to appreciate that although they were intuitively keen to give of their self to enhance therapeutic relationships, boundaries had to be drawn to prevent themselves from becoming emotionally depleted. Finding a balance between effective nursing and self-preservation was viewed as important, as captured by these nurses:

“You’ve got to look after yourself so it’s getting the balance right, you know, between being personal enough. You’ve got to give something of yourself for the patient to engage and build up that close relationship, whilst at the same time, be professional; it’s such a difficult balance.” (FG#4, NP23)

“I think, stoma patients are a vulnerable group of people, because it’s something we just don’t talk about, bowels, but to actually say you don’t go to toilet, you have your waste product in a bag, it’s all about bodily image stuff, esteem, sex, everything, you don’t want to get too embroiled in it because you could quite easily try and take everybody under your wing and try and solve the world and get yourself really bogged down, you have to have self-preservation because you get too involved.” (FG#6, NP34)

“I think sometimes you need to take the opportunity to actually look at how we work, you know, think about and accepting how far to go, to know how much to give of yourself, know what is my role and how much to leave for someone else.” (FG#7, NP39)

Having a sense of their own boundaries helped the nurses to remain emotionally in control. Overall, they demonstrated a balance between experiencing the emotions which allowed them to connect and understand the patient. This in turn encouraged cognitive activity and creativity in their specialist practice.

The nurses recognised the need for sensitive judgements with regards to boundaries between patients and their circumstances. An ongoing balancing act was evident between genuine caring and encouraging stoma care self-efficacy. Support was valued among the nurses and linked to assist the nurses with the emotional demands of their role. Some nurses spoke of careful patient allocation (FG#4, FG#7) so that more demanding patients were shared. Working as such offered peer support, team work where opportunities to share and reflect on their practice, either formally or informally, were appreciated.

7.7.4 The need to foster cognitive activity, good communication and creativity

The nurse participants frequently referred to the complexities of the specialist role as they described the challenges faced in their day-to-day clinical practice. They spoke of making decisions to resolve complex stoma care issues which were based on reasoning, perception and emotions. The nurses inferred being experienced, possessing specialist knowledge and skills as well as good communication assisted with the facilitation of such decision making, for example:

“Yes but to that you have to be creative with the resources you have. Specialist knowledge and experience helps but you also have to think on your feet, you know, for the sake of the patient, experiencing a dehist wound or a fistula is degrading enough without it being unmanageable for the patient”. (FG#7, NP37)

Referring to being ‘creative’ and ‘thinking on your feet’ inferred that creativity was not simply to ‘fix all’ (FG#7, NP38) but a challenge for the specialist nurse to act as a resource and develop practice, serve as a change agent and leader and become a role model within specialist practice. The nurses inferred that fostering such creativity required core cognitive

thinking skills and good communication so that they can give meaning to and learn from new knowledge enabling them to transfer it into other clinical situations:

NP2: "Your expertise develops from not always knowing, you know, you've got to remain open to new ideas and so that you can build upon what you already know. I know this makes some of my clinical decisions easier cos as a specialist nurse I'm continuously building on my previous knowledge.

NP4: Yeah, I agree but I also think it's about giving meaning to what you know. You might not be aware you know something until you need to use that knowledge and that's when your expertise grows. (FG#1)

This extract reveals how the need to appraise what is known supported the nurses' clinical judgement, and how such knowledge had been acquired through their clinical reasoning; establishing them as both a resource and a leader. This creative practice has the opportunity to offer new clinical experiences, flexible open learning and adaptability to transform them into expert practitioners.

A view shared by all the nurse participants was the emotional challenges provoked through close therapeutic relationships with their patients. They expressed the need to possess good communication skills and think creatively in their decision making. These challenges were often seen to extend to patients' relatives and other healthcare colleagues, particularly when trying to avoid mixed messages as previously presented (Stage 2 analysis, theme 'hurdles to accommodate'). The nurses described how using their emotions to facilitate thinking about a problem and to understand the implications of emotions in them and in others offered possible solutions to complex problems. These also include negotiations and interactions with other healthcare professionals as well as the healthcare organisation itself,

suggesting a deeper understanding of patient need evolves through the advanced communication skills of the nurse.

Within the focus group discussions, communication skills were seen to develop with experience and the ability to assess and 'pin-point' the needs of the patient was fairly instant:

"Quite often if you know the patient, you've had a relationship with them, you kind of are used to non-verbal communication sometimes with people, so you can just tell when they walk in, by their body language, whether they're upset or not." (FG#4, NP22)

Having experienced the clinical situation previously, enabled the nurses to be in tune with what was going on for the patient. Tuning in and gauging the patient's situation appeared to be gained through experience and reflection. Honing in on what was important for the patient and addressing that need was seen within the nurses' narratives as expert practice.

Verbal and non-verbal cues were also evident and shown to be complementary to understanding patients' need, with the more information the nurses had the better the outcome and resolution of the complex need/challenge described by the patient. As Mayer and Salovey (1997) indicate, tuning into and gauging mood reveals the nurse to be a perceptive emotional intelligent practitioner as one nurse participant expresses:

"..... awareness of the patient's non-verbal's is so important, you know, that one sigh can relay a thousand words, so you make eye contact, communicate clearly, listen and show you care". (FG#6, NP34)

It is evident that the slightest emotion shown by the specialist nurse can have an immense impact on patient care. Often taken for granted, what appears to be a simple moment, has the potential to have a profound effect on the patient's recovery.

7.7.5 Preserving a conscious awareness of self to develop personal growth

The nurses' narratives demonstrated that knowing who they were allowed them to reflect on their past experiences and consider their own beliefs and values. Consistent with Mayer and Salovey's (1997) theoretical framework for emotional intelligence possessing an awareness of self indicated that the nurses in the study were open and honest in the relationship they had with their patients. Being honest and self-aware allowed for open discussions with patients and alleviating any awkwardness between themselves and the patient. The narratives from the nurses demonstrated that they were in tune with their patients' physical and psychological needs. Knowing the patient and developing such close relationships have already been presented within the findings of this study (Stage 2). The nurses referred to this as being inevitable, particularly as they shared such an intimate relationship with their patients:

"We become very close to our patients. Their world has temporarily been turned upside down and to help them make any sense of this, we have to share private, intimate moments with them." (FG#7, NP36)

Developing such a close relationship was recognised among the nurses as they routinely engaged with the same patients so they were likely to develop an emotional connection:

“That’s what we always say to the patients, ‘For as long as you’ve got your stoma, you’ve got us,’ and I think that really – and the patients always say, ‘Oh that’s great.’”
(FG#1, NP2)

Such a relationship requires insight and self-awareness to manage each patient’s emotions through his or her journey; one which was described as being a *“traumatic experience”* (PT#4, female, 66 years, Diverticular disease) in phase 1 of this study.

Aspects of self and awareness of self were referred to by the nurses as an important feature of being a specialist stoma care nurse. Self-awareness was seen as the ability to become aware of *“who you are, as a person”* (FG#6, NP31). Knowing who you are was also seen by the nurses to offer opportunities to reflect on past experiences, core values, identity and strengths and weaknesses in their practice, a view shared by them all.

Aspects of awareness of self were demonstrated through the nurses’ insight into their own emotions and behaviours as illustrated:

“I feel myself getting hot and sweaty when patients start to ask me things out of my depth.” (FG#5, NP25)

“I was probably too new to, to have that insight.” (FG#3, NP13)

“I know you can’t engage with every patient you meet but I am aware I make more of an effort to engage with them if I sense our relationship is not a good one?” (FG#6, NP33)

“Really it’s our emotions and our feelings and how we depend on them. You know, what your mood is here (work) and at home. Sometimes I think we pass on our moods onto others, including patients.” (FG#7, NP36)

These narratives imply the nurses acknowledged that it was impossible to detach the personal component of nursing from the care for a person with a stoma. However, as long

as they had a conscious awareness of this, it revealed to them an acknowledgement of their strengths and limitations. This in turn offered them control to guide their subsequent behaviour. Paying attention to and being self-aware, formed the basis of the nurses' ability to reflect and learn from their behaviour. Attempting to be in tune with their emotions meant they could understand the emotions felt by the patient and give them an opportunity to talk and discuss how the patient was feeling.

Some of the nurses indicated the relevance of personal attributes to the role as a specialist nurse. In particular, the effect of up-bringing and life experiences were seen as influencing their beliefs and values, as well as personal growth, with a direct effect on emotional self-awareness:

"What life skills they've got and how they've shared that with you. Because if somebody shares something with you, also gives you permission to, you know, to think about it or, you know, acknowledge that we're all different." (FG#6, NP28)

"Life, I don't know, it's life experiences; it's to do with your personality." (FG#2, NP7)

"There are certain patients that you really, really click with, and there are some you don't. Thankfully working in a team means the patients care is not affected by personalities." (FG#5, NP27)

"Drawing on past experiences, from both your work life and personal life, helps you develop as a person, you know and we should share and learn." (FG#4, NP22)

The nurses referred to this as both a moral and 'emotional commitment' (FG#5, NP26) to the patient with a stoma. Aware of the profound effect of stoma surgery they demonstrated a genuine wish to support patients through their journey to adapt to the stoma:

"We (stoma care nurses) all want to help the patient cope with the changes they are having to adapt to, and if the patient really thinks they are going through a horrendous experience, then it's our duty to find out why." (Theme 1, vignette 1, FG#1, NP2)

Tuning in and gauging a situation was considered by the nurses to be an advanced communication skill gained through experience and reflection:

"Experience tells me those patients who present as an emergency, often don't show any bereavement or any kind of reaction. If there's no emotion then quite often they become more depressed and more anti their stoma later. So you assess and gauge the situation and pitch things so that you do things at their pace." (FG#2, NP8)

"You know, the skill is, to hold the patient without actually touching them. I mean sensing what it is that they are expressing, kind of being there but not being intrusive, having complete understanding without saying a word, totally in tune." (FG#6, NP32)

"I've noticed that recognising important life milestones for patients helps you tune into their needs, you know, they're disease free and the stoma might not be a problem now, but once they're married or have children, then all of a sudden the stoma becomes a major issue." (FG#5, NP27)

"I've learnt that you've got to go with the type of person they are, you know, try and normalise it for them." (FG#7, NP37)

"You can sit down and talk to them (the patient) about all of sorts of things, but you never know how a patient is going to react until they are there and have had the stoma, you know, and then that's, that's when we use our specialist skills and experience, to support them." (FG#4, NP23)

Working in a team was seen as important among the nurses not only for banter and maintaining comradery but also for troubleshooting and sharing caseloads, as illustrated by FG#6 and FG#5, when they stated:

"And if there is a problem, we try to troubleshoot. Our team has a variety of experiences so if I don't know then I'd call the other team and try and get help and support from them." (FG#6, NP33)

“And it made us, as a team, talk about what happens when we get someone who gets recurrence, so that we can share caseloads and no particular team member is swamped by patients demanding emotional care.” (FG#5, NP25)

This reflected the management of emotions to promote personal growth among team members and individuals. This ability to manage emotions is recognised with Mayer and Salovey’s (1997) emotional intelligence theoretical framework as an ability to be flexible to feelings and to control them in oneself. Previously identified at stage 2 of the analysis, supervision was seen as a valuable and positive tool for personal growth and development of the specialist stoma care nurse. The nurses cited ‘*sharing experiences*’ (FG#4), ‘*increasing self-awareness*’ (FG#6) and ‘*improving stoma care competencies*’ (FG#2) as valid reasons for receiving clinical supervision. Having the opportunity to reflect offered personal and professional development, as captured:

“..... exchange experiences, see and learn something new. Receiving supervision based on my own experiences and listening to others helps me grow in a way that makes me develop my specialist skills, you know, moving towards being an expert, as well as develop as a person.” (FG#1, NP2)

Others saw supervision as a way of sharing practice so that they could problem-solve and sought peer support from other specialist practitioners as described:

“I’ve not been in stoma care nursing long and supervision has given me confidence to try out new things, this patient’s bag kept leaking for no reason I could see and I was getting the feeling that the patient no longer trusted my advice, so I talked about it at supervision, turned out he had MRSA on his skin and the soreness was preventing the bag from sticking, since starting the recommended cleansing routine he’s had no problems and I learnt something new.” (FG#3, NP13)

Several of the nurses detailed what was meant in terms of learning and personal growth and development. Highlighting the need for positive and experienced role models in stoma care

nursing, this nurse described the need to have leadership that will motivate and develop practice:

“Yes well a good role model is imperative, you know, somebody who is a good leader, who can educate, motivate, ensure there’s good camaraderie. I think, you know, at the end of the day, we are here for our patients and developing practice is a sure way of ensuring best care.” (FG#6, NP28)

A shared view was the responsibility to learn within the specialist practice of stoma care. Learning, for the nurses, was about developing skills and competencies and ensuring that high standards of stoma care nursing were maintained. Constructive feedback received by the nurses from colleagues was seen as important, as it motivated individuals to ‘*continue to do my (their) best*’ (FG#2, NP9). The need for feedback among the nurses demonstrates the necessity for adequate and careful support in clinical practice. Clearly developing skills in self-awareness is essential for specialist practice as continuing to do their ‘*best*’, heightens self-awareness, aiding self-confidence and emotional self-control, as illustrated:

“Because you’re learning so much from one patient that can then help you, help the next one, so you want to learn as much as you can.” (FG#4, NP19)

7.8 Summary

The theoretical framework used at stage 3 of the analytical process re-examined the data from the focus group discussions. This offered new insights into how the nurses used their expert knowledge and experience, intuition and communication skills to make sense of clinical patient situations and offers clues to the pedagogical components required to prepare for specialist nursing practice.

There was recognition amongst the nurses of the important role they played to facilitate the adaptation needs of patients with new stomas. There was a sense of being needed and relied upon by the patients. Being a part of a patient's journey and having intimate relationships with patients and their families was seen as a '*privilege*' (FG#5, FG#7). Conflicts between their personal and professional self were raised. This not only led to blurred boundaries (FG#4, FG#5, FG#6) but also frustrations with the hurdles set by their organisations, in particular service provision (FG#2, FG#3).

The complexities of critical thinking, decision-making and clinical judgements have been recognised, whilst reflective practice through clinical supervision was seen to enhance the experiential learning experience. However, the findings also displayed a conflict between knowledge and intuition (FG#2, FG#4, FG#5). Addressing the psychological needs of patients was seen as an important aspect of the nurses' role however emotions influenced their thinking processes. The nurses shared the view that psychological support is a less visible role therefore difficult to determine and illustrate.

Emotional self-awareness allowed the nurses to question and make clear clinical judgements. Not being 'tuned in' or allowing their emotions to over-ride a clinical decision influenced the outcome. Clearly emotional self-control plays a significant role in the art and skill of specialist nursing practice.

The therapeutic relationship between the patient with a stoma and the specialist nurse was seen to be unique. Providing such fundamental care was shown to be essential in assisting

the adaptation process. The indication here is to foster and integrate current teaching practices to equip the specialist stoma care nurse.

7.9 Conclusion

This chapter has demonstrated the analytical approach to each stage of the analysis and articulated the knowledge and skills required of the specialist stoma care nurse to facilitate the adaptive needs of patients with a newly formed stoma.

Phase one of the study explored the challenges and experiences of patients having undergone stoma surgery. Their narratives clearly demonstrated the profound effect surgery and stoma formation had upon their lives. Experiences and the ability to adapt differed from one individual to another but similarities were also evident. A series of disruptions to their lives both physical and psychological have been described. The lived experiences as described by the patients stress the importance of information giving and transmitting this information in such a way that patients can prepare and develop coping strategies to help deal with their fears and concerns.

Ideally placed, a specialist stoma care nurse can gauge a situation by picking up on patient cues and facilitate the adaptive needs of the patient by tailoring the necessary information for the individual. The specialist nurse should have the knowledge and skill to deliver this information in a manner that is comprehensive to the individual patient.

Phase two of this study explored the complexities of navigating specialist knowledge and skills by the stoma care nurse to facilitate the patient's need to adapt to stoma surgery with a purpose of identifying pedagogical components of specialist stoma care nursing practice to inform educational delivery. This was made possible by creating the patient participant narratives into vignettes. The vignettes were used to stimulate discussion amongst the nurse participants in the focus groups. Overall, the findings highlight competent knowledge, skills, expertise and communication as essential to specialist practice.

The key feature of this study was to identify the knowledge and skills of specialist nursing practice to inform educational curricula. This was achieved through further examination using an alternative lens, namely the emotional intelligence theoretical framework of Mayer and Salovey (1997). Re-examining the data revealed the knowledge and skills deemed essential for specialist stoma care practice to make sense of clinical patient situations. From this perspective, the specialist nurses themselves, included expert knowledge and experience, intuition and insight and communication skills.

The following chapter offers a discussion of how the five essential elements, identified within the final analysis of this study, relate to specialist practice. Leading on from this, implications for practice, policy and education in connection to specialist nursing will be considered.

8. Discussion and implications

8.1 Introduction

Throughout the theoretical explanations of this process there has been frequent reference to the two connecting features of this study; the patient experience and the transmission of specialist knowledge and skills with particular emphasis towards adaptation. Both concepts underpin this work. It was hoped this inquiry would broaden the understandings of how specialist nurses transmit their knowledge and skills to facilitate patient's adaptation needs to living with a new stoma, to inform educational curricula for specialist nursing practice.

As seen in phase 1 of this study, patients with newly formed stomas experienced and displayed many types of emotions, which at times were seen difficult for the patient to translate. Each individual adaptive journey differed and preferences for the amounts and sources of information varied greatly as the patient narratives indicated. The ability to interpret and manage these emotions seems an important skill for the specialist stoma care nurse potentially enhancing holistic patient care and as Roberts (2010) highlights is pivotal in the development of therapeutic relationships.

This chapter discusses the findings from this study and considers the implications to practice, policy and education. The complexities of navigating specialist knowledge and skills by the stoma care nurse to facilitate the adaptation needs of patients with a stoma have been clearly demonstrated in this study and what is seen to emerge is a nurse who possesses expert knowledge and experience, an awareness of self and emotional self, empathy, intuition and insight and advanced communication skills in order to practice as a

specialist. This, in turn, reflects challenges for nurse educators to ensure educational curricula are specific enabling the nurse to develop and master such skills.

The decision to re-examine the phase 2 data through an alternative lens became apparent following the 2nd stage analysis where the findings were seen to be comparable with current literature and thus offering no new knowledge that would contribute to what is already known. It should therefore be acknowledged that the nurse participant's emotional intelligence abilities did not come under scrutiny during the focus group discussions. This said, the researcher also appreciates the consequence of using an emotional intelligence theoretical framework to guide a further analysis of the phase 2 data was likely to reflect such a perspective. Nevertheless, the nurse participants clearly demonstrated the characteristics of emotional intelligence leading to the emergence of the following essential elements to specialist nursing practice, these are,

- The influence of emotions on critical thinking and clinical decision-making
- The use of empathetic and intuitive skills in clinical judgements
- The ability to balance true self alongside professional self
- The need to foster cognitive activity, good communication and creativity
- Preserving a conscious awareness of self so to develop personal growth

A critical analysis will follow demonstrating how the five essential elements contribute to enriching an understanding of the nature and scope of specialist nursing practice.

Acknowledgment is given to the role and responsibilities of the specialist nurse as highlighted in Chapter 2, the experiences and perceptions of patients as illustrated in

Chapter 3. Chapter 4 investigated the pedagogical components of specialist nursing practice through the literature. Specifically the nature of knowledge and ways of knowing were discussed. This literature is now drawn on selectively, and together with further sources this chapter will offer broader clarifications to the inference of this study and articulate its contribution to practice, policy and education.

8.2 Discussion

For many years the profound effect of living with a stoma has been captured (Sunderland et al, 1952, Orbach and Tallent, 1965, Wade, 1989, Kelly, 1992, Haugen et al 2006, Danielsen et al, 2013b, Thorpe, 2014). These studies have also shown how the challenges faced by this group of patients have changed very little over time. Progressive changes in surgical techniques, drug therapies, bowel screening and patient recovery programmes are evident (See Chapter 2), but the practical and psychological effects of living with a stoma remains as profound. Phase one of this study mirrors the findings of these studies and highlights the patients' ongoing challenges as experienced by them at that time, illustrating how their experiences vary in both severity and duration.

It can be surmised, the patients within the study would have received much help and support in the preparation for stoma surgery by a specialist stoma care nurse as well as other healthcare colleagues. This would have included both physical and psychological preparation. However the critical appraisal within this thesis found insufficient attention has been afforded to the adaptation needs of patients undergoing stoma surgery inferring skills in the development of therapeutic relationships are not always fostered. Studies

acknowledge the provision of timely appropriate information as being essential to the patients' recovery (Chapple et al, 2006, Danielsen et al, 2013b, Haugen et al, 2006, Kvåle, 2007, Tarrant et al, 2008, Thorpe et al, 2014). However, the findings in this study highlighted, in some instances no amount of information would have prepared patients for living with a stoma. This suggests two points; first, information requires consolidating to a level of knowledge and skill that enables the patient to live with their stoma, confidently and competently. Secondly coping strategies should be taught in preparation for how the patient might cope with their fears and concerns, as Allison et al (2013) reiterates, stoma surgery is intended to improve quality of life. The specialist stoma care nurse is pivotal in facilitating the patients need to utilise their strengths and positive coping strategies to ensure this is fully attained. Findings from phase 2 indicated the nurses recognised this to be a key feature of their role demonstrating the need to possess a skilled know-how and good communication skills. This related to how they transmitted their knowledge and expertise as a specialist nurse but also reflected upon the need to know and develop a deeper understanding of the patient's need, thus developing what they described as an '*intimate therapeutic relationship*' (FG#3, FG#7) with the patient. This recognised the importance of establishing a relationship as a prerequisite to being aware and facilitating patients' needs as they adapt to a stoma. The essential elements emerging from the 3rd stage analysis infer how, for the nurse participants, this was reached.

The therapeutic relationships highlighted in the findings of this study suggested the interactions between the patient with a stoma and the specialist nurse are multifaceted, dealing with complex emotional and physical needs. In addressing such needs, the nurse participants recognised they were likely to encounter challenging conversations,

emphasizing how this would support them in developing a deeper knowing, connection and understanding of the patients' needs. In addition to this, Boot and Wilson (2014) draw attention to the skill of gauging the situation prior to embarking upon difficult conversations with patients. This was reflected in the findings as the nurses considered this an advanced communication skill gained through experience and reflection. Gauging the mood of the situation appeared to reflect on the nurses own emotional awareness enabling them to then focus on what was important for the patient. Mayer and Salovey (1997) indicated possessing and demonstrating such skills revealed the nurse as a perceptive emotionally intelligent practitioner. This ability to tune into and gauge the situation, for the nurse participants, was also seemingly eased by having a sense of them self.

This apparent awareness of self was seen as the ability to become aware of *“who you are, as a person”* (FG#6). It offered the nurses' opportunities to reflect on past experiences, develop core values, express their identity as well as consider their own strengths and weaknesses. This is congruous with the first and third branches and characteristics to Mayor and Salovey's (1997) theoretical framework for emotional intelligence (See Table 6.7) as it draws attention to how nurses need to perceive and understand their own emotions in order to provide a therapeutic relationship.

Due to the intimacy, the nurses appreciated it was almost impossible to detach their personal self when providing stoma care nursing. Mirroring Dowling (2008), the findings from the study highlighted the unavoidable closeness in the developing nurse-patient relationship. Indeed Kvåle (2007) suggests such a relationship cannot progress without becoming close and proposes such closeness will certainly enrich the nurse-patient bond. As

a consequence, the nurse participants acknowledged they would undoubtedly share unique aspects of self; an aspect of knowledge Carper (1978) and Jacobs (1998) referred to as personal knowing. They described how they had come to realise that although they were intuitively keen to give of their self to enhance therapeutic relationships, boundaries had to be drawn to prevent themselves from becoming emotionally depleted. Bailey et al (2011) support this in their study focusing on death and dying in the emergency department. They found building a close relationship whilst maintaining professional boundaries was challenging during highly sensitive, emotionally charged and often intimate moments. Dowling (2008) makes links between balancing personal alongside professional self; an essential element emerging from the findings of this study, illustrating the need to give of self but also to preserve self. The ability to position personal self within a professional helping role is central to the identity of the nurse and has previously been explored (Peplau, 1987, Öhlén and Segesten, 1998).

Evidence clearly links the possession of emotional intelligence capabilities to the development of close nurse patient relationships (Cobb and Mayer, 2000, McQueen, 2004) and understanding patient needs. This was also reflected in the findings of this study. The emphasis on awareness of one's own emotions and those of others, as portrayed by the nurse participants might offer an explanation for why some specialist nurses appear to be better at delivering patient-centred care than others. Fulton (2014) noted the need to have an understanding of how such emotions affect one's own behaviour and influences that of others. Indeed, when describing adaptation to the stoma in phase 1 of this study, the patient participants illustrated how their emotions fluctuated. In response, the nurses demonstrated their ability to recognise their own emotions enabling them to attune

themselves to those felt by the patient. Such behaviour suggested an appreciation of the depth, diversity and complexity of emotions. Clearer understandings of the significance of emotions seemingly eased the nurses' ability to facilitate adaptation and indeed intervene more effectively (FG#3) and likewise where misunderstandings of emotions were exhibited an absence of facilitation and intervention was perceived (FG#7).

The suggestion that moods and emotions play a central role in cognitive processes and behaviour and more specifically decision-making processes, indicates that the intuitive use of these emotions drive people to perform well (Downey et al, 2006, McConnell and Eva, 2012). The intuitive use of emotions on the part of nurses requires nurses to have the abilities to manage their own emotions to be able to respond to those expressed by their patients; this was clearly illustrated in the findings. Lam and Kirby (2002) emphasise this personal emotional management investment through their illustrations of how emotions affect cognition and cognition affects emotions, thus influencing behaviours and ultimately clinical decision-making. Amongst the nurses' narratives, there were illustrations of how gauging the mood, during patient consultations, was deemed important as a means of avoiding assumptions and misinterpretation of clinical situations.

Freshwater and Stickley (2004) also highlighted how our emotional world motivates our decisions and actions, prompted by memories and experiences from our past. However, emotions can turn what may appear to be a rational decision into a not so rational decision and as such is linked to emotional self-control. Tuning into the patients emotions, positive and negative, seemingly allowed the nurse participants to assess the situation and focus on what was important for the patient at that moment in time. McConnell and Eva (2012)

reported that both positive and negative emotions also play an important role as they influence how individuals identify and perceive information, how it is interpreted and how they might act as a result of the information available at the time. Various studies focus on the knowledge, skills and aptitude required of specialist nurses to undertake such a role (Worster and Holmes, 2008, Beaver et al, 2010, O'Connor et al, 2010, McCaughan et al, 2011, Lithner et al, 2012, Allison et al, 2013, Danielsen et al, 2013b, Husson et al, 2013, Wylie et al, 2013, Thorpe et al, 2014). These studies however, fail to capture what Trevatt and Leary (2010) describe as hidden aspects of the role; what skills are needed for the nurse to transmit specialist knowledge and skills to facilitate the patient need. This study therefore contributes to the body of knowledge by recognising the influence positive and negative emotions have upon specialist practice in relation to the critical thinking and decision-making abilities of the nurse.

The ability to know, understand and connect with patients without reasoning was described by the nurses as an influencing factor enabling them to problem-solve in an empathetic manner. The nurse participants viewed this as an evolving skill for specialist practice. This concept captures the development of proficiency and expertise as described by Benner (1984) and mirrored the knowledge and skills required of the specialist nurse. As their expertise and experience increased, skills of intuition interwove, and enhanced the ability to demonstrate empathy. This in turn intuitively led to a therapeutic intimacy between the patient with a stoma and the specialist nurse, a feature recognised by Kvåle (2007), Dowling (2008), Allison et al, (2013) and Thorpe et al (2014).

The findings illustrated how specialist nursing involves an awareness of having to understand the true meaning of what is communicated rather than simply the words that are exchanged, resulting in the need for precise identification of emotional responses in others. With ever changing healthcare practices, there is a possibility for empathetic responses to be lost. This was noted amongst the nurse participants as they discussed ways in which they were required to be creative with their information giving prior to surgery for patients in the advent of the enhanced recovery programme. They acknowledged the increasing complexities of patient care and the reduction in time to prepare patients adequately for stoma surgery. This is consistent with Eraut's (2000) two distinct elements of knowledge as the nurses expressed a need for the theoretical knowledge underpinning the protocols for the enhanced recovery programme whilst acknowledging the need to be intuitively empathetic to the needs of the patient. Mirroring the findings of Thorpe et al (2014), without such specialist skills, the ability to clinically assess patients may be over complicated, inferring the nurse participant maybe overthinking the situation and looking for something that maybe supposed.

The use of intuitive skills was referred to by the nurses as having a "*gut feeling*" (FG#1) and/or a '*gut instinct*' (FG#4). This indicated other ways of knowing their patient and the clinical situation. As recognised by Brown (2012) the nurse participants implied these skills developed through experience, highlighting how their perceptions, beliefs and practice transformed having met similar challenging clinical situations before. This allowed them to trust in and use their intuitive knowledge whilst problem-solving and decision-making for patients with a stoma. This is supported by Thompson et al (2008) and Dowding et al (2009)

who indicated specialist knowledge evolves through a combination of skill, expertise and ability but only becomes influential once meaning has been drawn from it.

Pooler and Plimley (2004) refer to the difficulties of making the transition from general nurse to specialist. Hill (2000) highlights how some specialist nurses possess specific qualifications for their specialist role but lack the experience of nursing at a senior level. It could be said that newly appointed specialist nurses revert back to 'novice' practitioners within their speciality during the transition to become expert in their chosen speciality. Although not a direct aim of this study, there was evidence within the focus groups that recognised the ability of the nurse specialist to work at an expert level clearly had an impact upon their ability to harness the competencies of emotional intelligence.

The assumption that the novice practitioner progresses in a straightforward approach towards expert practice ignores the ways in which learning style and experiences impact on individual growth and development (Benner, 1984). More recently, competencies have been considered as a combination of knowledge, skills, inspirations and personal traits (Roach, 1992, Carraccio et al, 2002). In this sense a competency can also be seen as the way someone performs; not in a sense as to whether they 'tick' a box but more their ability to think, to question and to reason (McGee, 2009). Recognition of this complexity has encouraged a different way of considering competencies, meaning that it could differentiate between an exceptional or mediocre practitioner (Freshwater and Stickley, 2004).

The ability to be creative within specialist practice was not seen by the nurses as an ability to '*fix all*' (FG#7) for the patient and other healthcare professionals but to act as a resource and develop practice, serve as a change agent and leader and become a role model within specialist practice. This is consistent with Munhall (1993) 'unknowing' as a way of knowing. The pattern of unknowing prompted the nurse participants to remain open to new ideas and beliefs thus avoiding closure of what was already known. This finding is comparable to Thorpe et al (2014), encouraging appraisal of what was known through their clinical judgement, and how that knowledge had been acquired by their clinical reasoning; establishing them as both a resource and a leader. This creative practice has the opportunity to offer new clinical experiences, flexible open learning and adaptability to transform to expert practitioners. Benner (1984) recognises knowledge increases as expertise grows, a denial of unknowing and satisfaction with one's own level of performance may hinder the development of expert practice therefore there is a need to foster such creative practices.

The nurse participants were seen to develop their own expertise by confronting their own reactions to challenges faced by patients through reflective practices. Being able to do this in a safe and supportive environment was seen not only to benefit the nurse but also offer the patient a better experience; Dowling (2008) refers to this as peer support and recognises this, in the form of clinical supervision. Indeed the findings referred to the nurses exploring their practice reflectively through clinical supervision enabling both critical and reflective thinking as a means to developing personal growth. These skills were also noted by Kuiper and Pesut (2004), as desirable for making clinical decisions and judgments in advanced practice. Such guided reflection is also attributed to a pattern of knowing (Johns, 2000).

Supporting this, Caffey et al (2012) noted in their study, that clinical supervision for occupational therapists could be enhanced if it focused not only on practice issues but also understanding and using emotions within practice. This was also reflected in the management of emotions to promote personal growth amongst the nurses in this study. Consistent with the characteristics of managing emotions (Mayer and Salovey, 1997) supervision was seen as a valuable and positive tool for personal growth and development of the specialist stoma care nurses allowing for the sharing of best practice, peer support, learning about personal growth, developing skills and competencies for specialist practice, heightening self-awareness and emotional self-control and gaining confidence. Sharing aspects of self, as described by the nurses, increased an awareness of each other's emotions often guiding them in how they should behave as well as influencing their clinical judgments and decision-making.

Effective communication promotes disclosure of feelings by the patient from which patients gain emotional relief (Jack and Smith, 2007). Other studies have indicated that nurses often give low priority to allowing patients to express their feelings, indicating an unmet need (Kvåle, 2007, Ream et al, 2009, Beaver et al, 2010, Danielsen et al, 2013b, Wylie et al 2013, Leary et al 2014). It was evident from the nurses' narratives that good communication was a key feature of their role. They described using their emotions to facilitate thinking about a problem and to understand the implications of emotions in them and in others so to offer possible solutions to complex problems. This may also include negotiations and interactions with other healthcare professionals as well as the healthcare organisation itself as illustrated in the findings.

Thompson et al (2008) and Dowding et al (2009) suggested that complex decision-making by a better educated nurse may not be the primary manner by which they produce better clinical outcomes. This suggests the nurse may possess the knowledge required but lack the skills in transmission for the patient to grasp. The findings from this study suggest that skills in emotional intelligence play an important role in aiding the specialist stoma care nurse to develop an intimate therapeutic relationship and consequently, effectively engage in the facilitation of patients need as they adapt to a stoma. For the participants in this study, as well as those within the literature explored, there appears to be grounds for raising awareness as to the importance of emotional intelligence skills being integrated into the specialist nurse educational curriculum; the implications for which will now be explored.

8.3 Implications for clinical and academic nursing

Healthcare provision in the future is recognised as a challenge. Care and service provision provided by specialist nurses are often considered to be expensive and therefore the specialist nurse needs to develop skills and competencies to justify and secure their future. Indeed, current financial constraints have led to further scrutiny of the specialist nurses role, highlighting the need for nurses to demonstrate their worth (Leary et al, 2008, Oddsdóttir and Sveinsdóttir, 2011, Norton et al , 2012, Leary et al, 2014).

A recent government document sets the political vision for the future outlining the principles for patient care in the coming years (DH, 2010). This puts patients at the heart of services, focusing on clinical outcomes and empowering healthcare professionals. However, there is debate as to what constitutes skills and competencies and their relevance to the

educational curriculum development for the specialist practice. Unless these skills and competencies are viewed in a broader perspective they are capable of appearing insignificant (Freshwater and Stickley, 2004, Sephton and Kemp, 2013).

The findings presented have implications for specialist practice and education and in terms of roles and responsibilities, policy and regulations too. Abilities in emotional intelligence are related in part to the individual and as such require thoughtful attention from educators', managers and strategic level policy makers.

8.3.1 Specialist practice

This study recognised the importance of establishing a nurse-patient relationship as a prerequisite to being aware and facilitating patients' needs as they adapt to a stoma. Essential skills of the specialist nurse were seen to provide intimate individualised care to all patients through the abilities of emotional intelligence. This inferred emotional intelligence to be a key part of the less obvious but crucial practical knowledge required of specialist nurses enabling them to translate information in a manner appropriate for the patient to grasp.

The navigation of complex clinical situations both emotionally and ethically have been illustrated in the study. However, the struggle to manage and maintain emotional well-being was also noted, particularly when caring for an emotionally intense patient over a long period of time. The work of Hochschild (1983) and Smith (1992, 2012) suggests understanding emotional management as key towards managing emotions. Both authors

referred to this as emotional labour. They highlight that when nurses did not feel as they think they ought to feel in particular situations, they engage in emotional labour to manage, control or alter their emotional status to correspond with what they believe is appropriate for the situation. The results of this engagement can be emotional detachment which could compromise patient care. This clearly resonated with one of the focus group discussions, as illustrated in the findings (FG#7), where the emotions of the stoma care team seemingly overshadowed the need of the patient, a realisation, as a team, they all found difficult to comprehend. This indicates a need to increase the feeling of control and emotional competence to assist specialist nurses to adapt an active and effective coping strategy to deal with stress, which in turn will enhance their well-being.

Whilst it was evident that the nurse participants in this study were aware of their professional and personal boundaries some were described as being clear cut and others not so. The ability to balance true self with professional self was seen as a skill by the nurse participants that was used as a way of managing emotions. Perhaps as individuals examine self, perceptions and insights through reflection these reflected responses might provide a deeper awareness about self and its congruity. Overall, the nurses demonstrated a balance between experiencing the emotions which allowed them to connect and understand the patient. This in turn encouraged cognitive activity and creativity in their specialist practice.

Specialist practice should be viewed as a level of practice rather than a specific role and should not be exclusively characterised by the clinical domain but also include skills in emotional intelligence. A more detailed perception of the characteristics of specialist practice based on Mayer and Salovey's (1997) emotional intelligence theoretical framework

as illustrated in Table 8.1 could be considered. The application of such features lends itself to support the development of an intimate therapeutic nursing relationship. Akerjordet and Severinsson (2004) affirmed that emotional intelligence integrates important personal and interpersonal skills which can lead to flexibility in handling change and better quality of care in the future, creating a more humanistic, compassionate and healing environment with healthcare.

Table 8.1 - Characteristics of emotional intelligence for specialist practice adapted to fit within the branches of emotional intelligence of Mayer and Salovey (1997)

Branch 1	Branch 2	Branch 3	Branch 4
Perceiving emotions (PE)	Facilitating thought with emotions (FE)	Understanding emotions (UE)	Managing emotions (ME)
Characteristics <ul style="list-style-type: none"> • Conscious awareness of self • Perception of feelings • Appraise and express emotion • Tuning in • Sub-consciously gauging mood 	Characteristics <ul style="list-style-type: none"> • Intuition • Control emotions • Innate behaviour • Cognitive process – comprehension of language • Creativity • Initiative • Flexibility • Transparency 	Characteristics <ul style="list-style-type: none"> • Experience • Interpret emotions • Empathy • Self compassion • Aptitude • Cognitive activity • Clinical reasoning • Critical thinking • Metacognition • Clinical judgment • Problem-solving 	Characteristics <ul style="list-style-type: none"> • Communication • Inspirational Leadership • Facilitation • Motivation • Therapeutic relationships • Personal growth of self and others • Change agent • Influential • Teamwork and collaboration • Reflection • Clinical supervision • Influences - beliefs and values

Specialist nurses who engage in developing an intimate therapeutic relationship have an increased ability to explore their patients' information needs and in doing so are better able to respond to those needs and assess patients' understanding of information.

8.3.2 Education

Hegarty et al (2009) clearly outlined the challenges currently confronting the future of nurse education. They specifically identified the following: changing patient characteristics, science and information technology, increased complexity of health as well as regulators updating policy and professional standards as a response. In addition, this study infers skills of emotional intelligence to be a key, challenging nurse education to move away from content driven curricula and foster new pedagogies that have a flexible learning-centred approach.

To date the goal in developing specialist practice curriculum is to identify advanced knowledge and skills common to all aspects of specialist practice and to differentiate between the common and specialist content necessary to support clinical expertise and designated areas of practice. An innovative, critically reflective curriculum design is necessary and this demands much from the educationalists. In keeping with the NMC guidelines if the nurse is to register as a specialist practitioner then they must gain skills that are far beyond anything learned or done previously as a registered nurse. However this study demonstrates that possession of specialist knowledge and skills is not necessary enough to warrant the title of specialist nurse inferring skills in emotional intelligence requires some consideration into the current curriculum for specialist practice.

There is currently a lack of empirical work exploring the true worth of embedding emotional intelligence into specialist nursing curriculum. This might reflect upon the question, as to whether emotional intelligence is a skill (Mayer and Salovey, 1997) or personality trait (Goleman, 1998) or indeed a combination of the two. Nevertheless some authors have argued that emotional intelligence cannot be taught in a traditional manner (Zeidner et al,

2002, Brackett et al, 2006, Danielsen and Cawley, 2007) whereas others suggest competencies in emotional intelligence can be taught (Lynch and Cole, 2006, Downey et al, 2006, Benson et al, 2012). This argument is likely to continue however this study contributes to this body of knowledge by demonstrating the value of emotional intelligence in specialist nursing practice, inferring a more contemporary approach to curriculum development is just what specialist nursing needs.

For this to be achieved current curriculum should be challenged, allowing the taken for granted educational practices to move away from educational programmes which are built with the goal of delivering massive amounts of content to an approach that encourages nurse educators and learners to reveal their experiences of teaching, learning and thinking (Horsfall et al, 2012). By exploring the knowledge and skills required of the specialist stoma care nurse this study infers any new pedagogies need to integrate descriptive knowledge with patient care, clinical and leadership skills, emotional intelligence and evidence based practice so to have the foundation to develop emotionally and intellectually competent specialist nurses and thus bring a new level of curricular sophistication incorporating a precise pedagogy for specialist stoma care nursing.

With the call to significantly modify nurse curricula (Benner et al, 2010) there is enormous potential for innovation and creativity to improve and consider the educational strategy for specialist nursing. There is pressure to make academic practices more cost-effective, user-friendly and accessible to all. As a result preferences for online education are on the increase (Adams and Timmins, 2006, Moore et al, 2007, Axley, 2008). Key questions as to whether an online approach to teaching is the way forward needs closer examination,

particularly as the essential elements required for specialist practice highlighted in this study suggest face-to-face contact teaching as preferable. So financial pressures for study leave, releasing nurses from the clinical environment and academic study costs result in these methods of teaching potential being viewed as less favourable.

Assessing the value of teaching skills in emotional intelligence has a number of challenges for nurse educators mainly because of the differences in its concept, i.e., ability or inherent personality. For integration to take place the framework for emotional intelligence should have a solid conceptual framework. Evidence throughout this thesis clearly links emotional intelligence to developing close nurse patient relationships and understanding patient needs, however, currently there is no evidence to suggest emotionally intelligent practitioners make a direct difference to patient outcomes.

Bulmer-Smith et al (2009) reported that emotionally intelligent leadership might be a key to translating knowledge particularly where evidence is valued in practice. There is therefore a need, as suggested by Freshwater and Stickley (2004), for emotional intelligence to be placed at the heart of the curriculum. If this is the case, then nurse educators need to have an understanding of their own emotions in order to facilitate student teaching and learning (Allen et al, 2012). This may well bring some out of their comfort zone but as Benner et al (2010, p8) pointed out, there is a need to get away from what they describe as a culture of the 'canned PowerPoint teaching' and become more creative and explore varying teaching methods that looks to support various styles of learning. Changing the perspectives on an academic culture that is already burdened with increasing costs and reduced budgets will

not be an easy task; however, the theory practice gap will continue to extend unless nurse education can review its approach.

Benner et al (2010) suggests nurse educators need to have a clear articulation of their teaching practices and must strive to teach a student, to nurse, who uses evidence-based knowledge and cultivates habits of thinking for clinical judgement and skilled know-how. There is a sense that nurse educators need to develop a special body of knowledge that exceeds descriptive knowledge. Such knowledge would enable nurse educators to translate descriptive knowledge into effective teaching strategies to meet the learning needs of the learner. If emotional intelligence is to be integrated into specialist nurse education, the nurse educators' primary role is to foster intuitive thinking, encourage intrinsic motivation and interest, translate information into appropriate learning styles, and provide learning environment, materials and activities to meet individual needs of students.

8.3.3 Policy

The continued lack of guidance by the NMC has led to inconsistencies in the roles and responsibilities of specialist practice. The value of policy and regulation is to guide the development of specialist nursing and subsequently inform curriculum development. The emphasis for the NMC (2015) is to produce individuals that are fit to practice, that is to say they have the skills, knowledge, good health and good character to do their job safely and effectively, however, educational requirements for specialist practice remain unclear (McCorkell et al, 2015). An all graduate nursing profession is likely to address some of these areas however a lack of clarity is still reported (McCorkell et al, 2015), indicating the need for the NMC to reconsider the regulatory framework to guide specialist practice and an

opportunity for the consideration to include skills in emotional intelligence. Further refinement and clarification is therefore needed, taking into account the complexity and variability of practice, for this then to influence educational curricula for specialist practice. Such a framework needs to develop a key to understanding its contribution to the future of specialist practice and should be pertinent to all contemporary debates regarding specialist practice.

8.4 Conclusion

The education for emotional intelligence has not previously been considered an essential and related part of the competency for specialist nursing practice. The focus of this study has been to explore how specialist nurses transmit their knowledge and skills to facilitate patient care so to inform educational curricula. Curriculum designers are tasked with creating an educational strategy that will prepare specialist nurses for specialist practice.

This chapter has considered the findings from this study and their implications to practice, policy and education. A curriculum model and educational strategy that will integrate the specialist skills of stoma care nursing whilst also developing a competent emotionally intelligent practitioner is evidently needed. Possessing such skills has the benefit of closing the knowledge gap and easing the translation of knowledge in a way the patient can grasp, thus assisting them through the profound changes brought about by stoma surgery. In this respect, the present study provides a valuable, unique contribution to existing knowledge inferring the integration of emotional intelligence into specialist nurse education provides nurses with greater opportunities to understand themselves and the way that they develop

relationships with others (Evans and Allen, 2002, Freshwater and Stickley, 2004, Hurley and Rankin, 2008), in turn, equipping patients with the skills to cope with their fears and concerns suggests their ability to adapt might not be as overwhelming.

9. Reflection and reflexivity

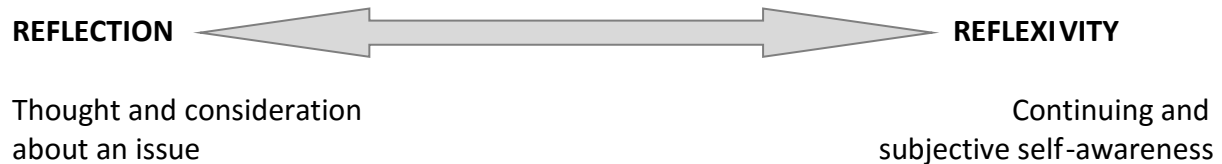
9.1 Introduction

During the study, it was essential that an open and transparent interpretation was maintained. Reflection and reflexivity are both linked to qualitative research (Engward and Davis, 2015). For the purpose of the study, they have become an important feature of the audit trail, ensuring the study's trustworthiness. Reflexivity, the 'capacity to reflect upon one's actions and values' (Arber, 2006, p147), should ensure confidence, scrutiny and credibility in the researcher. It is an opportunity to systematically reflect on the researcher's part in the process and the events that are occurring, alongside how they might fit into the bigger picture. It is seen as developing insight into the researcher's work and applying a critically analytical approach (Koch, 1998, Atkins, 2000, Birks and Mills, 2014). Cutcliffe (2003) suggests reflexivity is the base for explaining the rationale behind the judgment calls made within the research process. This also offers an opportunity to have courage to know when to stop looking for something important that is not there; allowing the researcher to focus on what has already been perceived the area of significance.

Finlay (2002, p532) defines reflexivity as a '... thoughtful, conscious self-awareness. Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself. It involves a shift in our understanding of data collection from something objective that is accompanied through detached scrutiny of "what I know and how I know it", to recognising how we actively construct our knowledge'. Some authors have highlighted the confusion between reflection

and reflexivity and propose these words are actually on a form of continuum (Finlay, 2002, Colbourne and Sque, 2004) (See Figure 9.1).

Figure 9.1 - Reflection-reflexivity continuum (adapted from Colbourne and Sque, 2004)



At one end of the continuum reflection suggests the ability to give an issue some serious thought and consideration, evaluate it and learn from the process, whilst at the other end, reflexivity involves more of an immediate active and subjective self-awareness. Perhaps the most difficult aspect of reflexivity for a researcher is to recognise precisely how to achieve this and where on the continuum a researcher moves, from reflection to a reflexive approach. It is for this reason I have chosen to combine both reflection and reflexivity, so that I can demonstrate how aspects of the research influenced the decisions I made during the research process. As this is a personal reflective piece, I will continue to write in the first person.

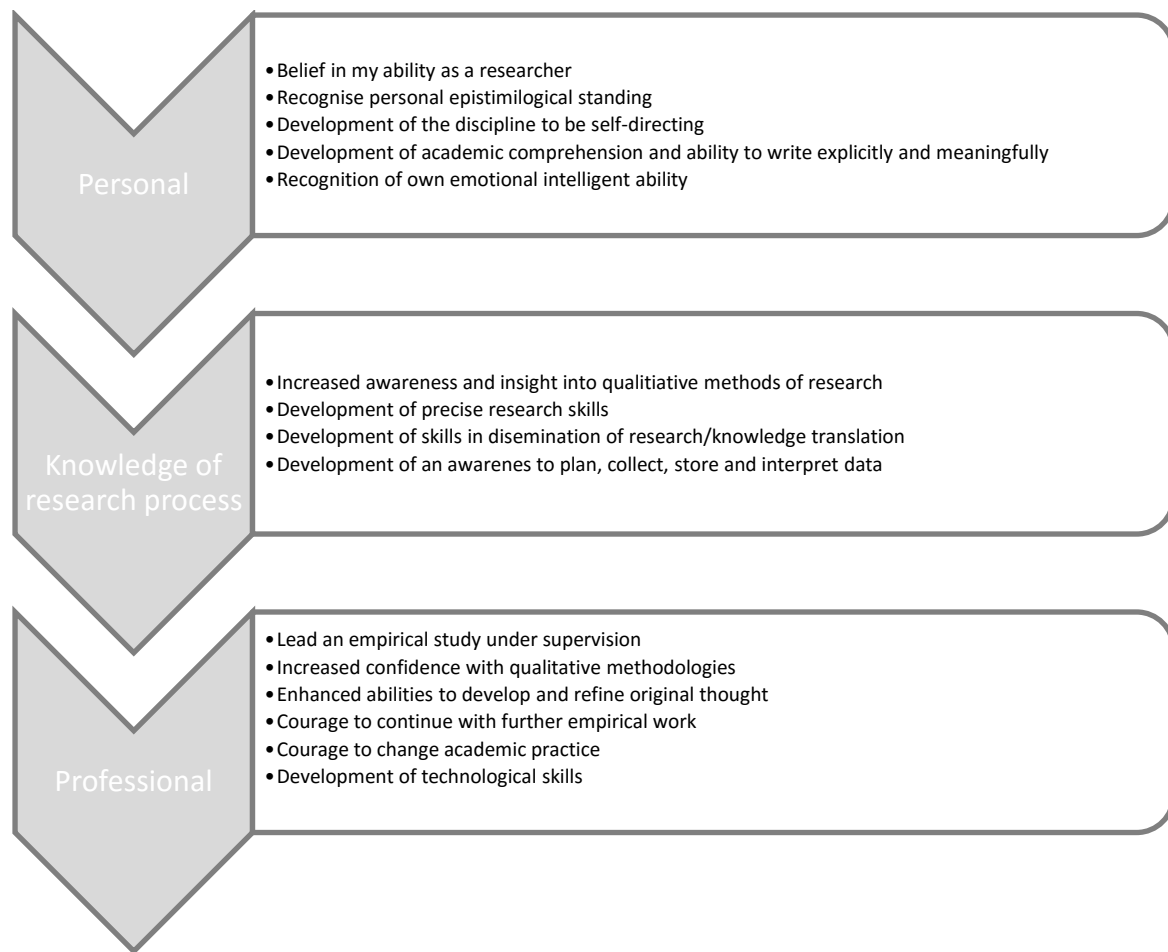
This study derived from an awareness of the diverse and complex issues of stoma care nursing. I have worked within the speciality for over twenty-five years, and have been in a privileged position to not only care for patients undergoing stoma surgery but also be instrumental in the development of educational programmes for specialist stoma care nursing practice. Patients' experiences and needs are well documented in the literature; extending knowledge and informing clinical practice. Aware of the profound effect of stoma

surgery on a person, from an educational perspective, I felt there was a need to inform specialist education to ensure specialist stoma care nurses were equipped with the knowledge and skills to facilitate the patients' adaptation needs.

During my research journey, I kept and still maintain a reflective journal with the purpose of adding to the participants' interpretations and focus group discussions, as part of the analysis and to aid this reflexive piece. Keeping the journal entailed making some personal notes before, during and after each interview and focus groups as well as in between. I was able to reflect on the data collection process, what areas I felt could be improved and start to make sense of my findings, as interesting topics arose at interview or within the focus group discussions. The journal became invaluable, as ideas come in to my mind, day and night, and I was able to jot down notes so that any ideas were not lost or forgotten.

My reflexive journal represented a space where I could consider the observations that I had made, and what impact my own personal experience would have on my interpretation of the data. Having worked directly and indirectly in the field of stoma care, I was aware that my own preconceptions might influence how I approached this piece of work. Using the reflexive journal was a way of acknowledging my subjectivity, as it helped me focus and set aside my preconceptions and focus on what the participants from both phases of the study were telling me. The reflexive journal also assisted with the detailing of any incidents, for example, when a patient was upset or appeared to be distressed. As part of my ethics application, I was required to consider this and refer to the specialist stoma care nurse as necessary. Figure 9.2 illustrates my personal and professional key learning points, which will now be discussed as I reflect on my research journey.

Figure 9.2 – Personal and professional key learning points



9.2 Reflecting on my research journey

Preparing for the approval of my study by the Ethics Committee, I was able to consider my proposal for this empirical study and in doing so, consider my ideas and concepts and eventually refine my original thoughts. The rationale for this study has already been explored but the inspiration for this work derived from an awareness that much of the literature to date informs clinical practice but omits to recognise the content and structure which informs educational delivery, particularly when supporting specialist nurses in the clinical setting. Anecdotally, whilst observing specialist clinical practice and discussing clinical issues in the classroom I could see that some specialist stoma care nurses appeared

to be better at facilitating adaptation needs and information to stoma patients, than others. I had no clear understanding why. Was it an inherent personality or an acquired skill? And as a nurse educationalist was it something that could I teach? I therefore set out to explore the abilities of specialist stoma care nurses in transmitting their knowledge and skills to facilitate the adaptation needs of patient with newly formed stomas to inform educational curriculum.

I had always perceived that I would utilise qualitative methodology, as the philosophical underpinnings are in line with my own beliefs and values; however, this then forced me to consider my own thoughts and beliefs about knowledge, research and my epistemological view. Reflecting on my own philosophical and ontological perspectives, it became clear that I naturally sat within a constructivist paradigm. Knowledge for this study is based on the concepts of others' perspectives of life, that is, to develop an understanding of human beings and their experiences. I believe knowledge and learning is an active process of creating meaning to such experiences. As Holloway and Wheeler (2010) state, the social world is unable to exist without human beings who innately build their own social reality through life experiences. A phenomenological approach was chosen because this not only suited my own beliefs, but kept the orientation of the research to the participants' subjective perceptions, valuing both individualism and holism thus allowing this experience to be fully described.

Phase one of the study was based on two sites. These two sites were chosen because of their national recognition for excellence in colorectal surgery and nursing. My own leadership and management skills were required as not only did I need to brief the specialist

nurses with regards to the study, I then realized that whilst in full time employment I had to plan how best to carry out the interviews in a timely manner. I had to learn to succinctly explain the study, ensuring those indirectly involved were fully briefed. This was helpful in providing a focus to the study and also, reassuringly, provided confirmation of the overarching aim and objectives to the study.

The patient participants were offered an interview in the hospital or at home. All of them choose to be at home. I was pleased, as I knew being in an environment familiar to them would enable them to feel relaxed. I was also mindful of my employing Healthcare Trusts, lone worker policy and ensured this was adhered to. Although I was not known to any of the patient participants, wearing different clothing to my usual work outfit, to me symbolised a changed in self-identity, allowing me to take up the role of researcher rather than healthcare professional. This served to make what was familiar to me, less so, allowing for the patients stories to be heard. The patients welcomed me into their homes for which I was truly grateful.

Armed with taped recorder and reflective journal I proceeded to carry out the data collection for phase one. Confidence in my interview skills increased with practice, aided by the topic guide (See Table 6.2). Consistent with the phenomenological approach, I was able to verbalize any perceptions I had so, that the patient and I spoke with a similar understanding. This was also achieved by summarizing the essence of the stories shared by the patients, with the patient, at relevant points during the interview to seek clarification.

Questions within my topic guide and responses to the patients during the interview were partially shaped by my own experiences of caring for people with stomas, whilst working as a specialist stoma care nurse. I particularly recalled the pre-operative information I would provide and the practical and psychological support immediately post-operatively. Being familiar with terminology and using language regarding the stoma that the patients could identify with, I feel eased the interview process. However, I felt the need to keep the philosophical underpinnings of the phenomenological approach in the forefront of my mind. I found Boeree's (1998) prompts for phenomenological interviewing (See Table 9.1) particularly helpful for this as it ensured I stayed true to the approach. These prompts proved useful for the data collection at both phases of the study.

Table 9.1 - Boeree's (1998) prompts for phenomenological interviewing

Boeree's prompts
<ul style="list-style-type: none"> • Was I fully present, phenomenologically? (Or did I sink into a routine, a sort of semiconscious scribbling?) • Did I take care to not allow my own ideas, desires, interests, needs to distort the interview process? • How was my aesthetic sense? • Did I see the pattern or essences? • Did I communicate them to the reader as the interviewee would have wanted to me to? • Did I check my intuitions with the person by reflection or simply by asking? • Did I capture the person, as well as the topic? • Did I capture the conversation, the flow of words and ideas between two real people in a real setting?

I was moved by the openness and frankness of the patients' experiences as they shared their stories. Life for some of them had truly become overwhelming. In the main, the patients were positive towards their stoma, having rationalized its reason for being there. It

was humbling to see some patients re-evaluate their lives and consider what was actually important to them. Others felt their experience was still 'raw' and may have not spoken so freely. I was completely aware the interviews would be in the context of the here and now and I was keen to gain a rich in-depth snapshot of this experience for them, sharing what was real to them at that moment in time. However, I was also aware of the pitfalls this might bring but unfortunately ethics approval had not awarded me the opportunity to re-visit the patient participants for a follow-up interview. In view of this I was aware that some patients might not have experienced the return to the lifestyle they knew previously in totality. However this meant that the vignettes created from the patients' narratives for the focus group discussion were presented in context and at their most pure, offering richness to the data collected. Data saturation became apparent, because patients began to express similar experiences of having undergone stoma surgery. I was however aware, that although my previous clinical experiences allowed me to hone in on relevant aspects of their experiences, I may have moved the interview discussion along more rapidly than was needed, potentially losing some rich data.

Following each interview, I took it upon myself to transcribe each taped interview. A huge learning curve ensued as I mastered the art of transcription; 1 hour interview = 8 hours of transcribing. This however was invaluable as I was able to immerse myself fully into the data and make sense of their experiences and create representing themes. In contrast, I chose not to transcribe the focus group data and used part of the awarded Seed Corn Grant to pay for this to be carried out professionally. With hindsight, if I had had the time, I would have preferred to undertake this myself. Even though I was present at the focus group discussions and commented in my journal, I found the focus group transcriptions much

harder to grasp in their true meaning and found myself reading and re-reading them copious amounts of times. Eventually reading and listening simultaneously, solved the problem, as listening triggered memories, enabling me to re-call the actual event.

Recruiting nurses for the focus group discussions proved disappointing. Specialist stoma care nurses were initially recruited from their annual national conference for stoma care nursing (Association of Stoma Care Nurses UK). I created a flyer inviting the nurses to participate and was given permission to place one within the delegate pack. The flyer outlined the study aim and objectives and offered my contact details should anyone wish to discuss my study further. A total of 420 delegates attended the 2011 conference and 9 specialist stoma care nurses responded with an interest to take part in the focus group. This unfortunate response meant that I needed to re-think my recruitment strategy.

As part of a separate project, I had been invited to facilitate a number of road shows regarding psychosexual issues and the patient with a stoma by an ostomy appliance and supply company. The road shows moved around the country where I had an ideal opportunity to recruit from a purposeful sample. Fortunately the company financially supporting the road shows agreed to time table 1 hour into the programme in order for the focus groups to take place (See Table 6.5). The nature of the road shows reflected similar issues to those of the study so I was mindful that those attending were likely to be more willingly to take part, already had an interest and desire to explore issues relating to the study.

During the focus groups, I had to acknowledge my own thoughts with regards the nurses' responses, through the facilitator, especially when some of the responses varied with my own and the literature. This also ensured we had reached a shared meaning. This was particularly important as I was known to all the nurse participants, through my role as nurse educator. Mindful of this, I did not want to inhibit their discussions and therefore I took up the role of observer, making notes in my journal whilst an experienced facilitator, unfamiliar to them, chaired the groups.

The vignettes were used to trigger discussions relating to the experiences of patients who had undergone stoma surgery. I felt that the nurses thought these were cold and unfamiliar to them; however, they served their purpose as indeed discussions around similar clinical scenarios from their own clinical practice were openly discussed. This data offered a rich insight into their daily clinical practices emphasizing their specialist knowledge, skills and expertise.

During the analysis, I was aware I needed to remain transparent and ongoing reflexivity helped me shape my analysis. The use of coding assisted with this. However, whilst interpreting the data I was constantly aware of my inherent influences. To overcome this, I have presented the participants narratives as verbatim, in order to support my interpretations. I am aware that the literature in relation to my study, omits to inform educational constructs for specialist stoma care nursing practice. I was conscious therefore not to make my research fit with what I wanted it to be in relation to the literature and my assumptions. This was evident following the 2nd stage analysis (See Figure 7.4), when it became evident that my findings at this stage were comparable to current literature. I

discussed the themes at length with my supervisors and toiled with my interpretations. Realizing that my overarching aim had not been achieved and no new knowledge was apparent I took the decision to re-examine the data using a different lens and undertook a third stage analysis (See Figure 7.6). The complexities of data analysis were realised as the nurse participant's emotional intelligence abilities did not come under scrutiny during the focus group discussions. This said, I also appreciated the consequence of using an emotional intelligence theoretical framework would reflect such a perspective. Never the less, I feel this became the turning point for my study; the 'light-bulb' moment, particularly as my original thoughts and refined ideas had come to fruition as the nurses clearly demonstrated such characteristics.

Supervisory discussions during my research journey were integral to each stage. The receipt of constructive feedback has been invaluable providing me with the support and encouragement to carry on – even in those darkest moments. We discussed issues I had noted in my journal and met frequently to discuss these issues. Early in the interview process, I forwarded one anonymized transcript to my supervisors for them to assess my interviewing skills. I was guided to undertake supportive training and found the 'Good Clinical Practice' training useful. As too was the Nvivo training, although I chose not to use this route, and the 'long document' course.

9.3 Conclusion

Being reflexive has helped illuminate and challenge some of the realities that surround this study. I thoroughly enjoyed the period of data collection as I felt I had a true sense of the

qualitative methodology and was in control of the research process. From a phenomenological stance, reflexivity is embodied through the notion of intentionality. This is the inseparable connection to the world, the act of researching, questioning and theorizing, as an intentional act of attaching ourselves, or becoming the world (van Manen, 1990).

10. Conclusion

10.1 Introduction

Achieving the overarching aim and objectives has resulted in this two phase qualitative study identifying the transmission of knowledge and skills of specialist nursing practice. As a result this study proposes the integration of emotional intelligence into the specialist nurse educational curricula as an educational strategy to equip specialist stoma care nurses with the ability to translate knowledge and skills to facilitate the adaptation needs of patients with a stoma.

This study has identified the therapeutic interactions between the patient with a stoma and the specialist nurse to be multifaceted, dealing with both complex emotional and physical needs. Inferences was made to knowing and understanding patients' needs intuitively, seemingly led to a deeper therapeutic intimacy between the patient with a stoma and the specialist nurse.

Much of the empirical work to date relates to the development of the concept of emotional intelligence (Bar-On, 1997, Mayer and Salovey, 1997, Goleman, 1998) and the formation of assessment measuring tools (Bar-On, 1997, Mayer et al, 2002). Laterally research has explored the integration of emotional intelligence into varies areas of nursing practice; mental health nursing (Akerjordet and Severinsson, 2004, Hurley and Rankin, 2008, Hurley, 2012, Chaffey et al, 2012), nursing management (Downey et al, 2006), knowledge transfer (McConnell and Eva, 2012), recruitment (Rankin, 2013), community nursing (Davies et al, 2010), nursing (McQueen, 2004, Por et al, 2011), cancer care (James et al, 2010, Codier et al,

2011) and death and dying (Banning and Gumley, 2010, Bailey et al, 2011). However, no research related to the impact of possessing skills in emotional intelligence has upon the translation of specialist knowledge and skills to facilitate patient care, thus making this an innovative study.

This lack of empirical work between emotional intelligence and nurse education might reflect the question, as to whether emotional intelligence is an ability (Mayer and Salovey, 1997) or personality trait (Goleman, 1998) or indeed a combination of the two. Nevertheless some authors have argued that emotional intelligence cannot be taught in a traditional manner (Zeidner et al, 2002, Brackett et al, 2006, Danielsen and Cawley, 2007) whereas others suggest competencies in emotional intelligence can be taught (Lynch and Cole, 2006, Downey et al, 2006, Benson et al, 2012). This argument is likely to continue however this study contributes to this body of knowledge by demonstrating the value of emotional intelligence in specialist nursing practice and proposes achievable educational strategies. On the grounds that those health care professionals who communicate better and demonstrate higher levels of professionalism, are more emotionally intelligent, suggests this is just what specialist nursing curricula needs.

This chapter will continue with a critique of the research method, highlight the limitations of the study and consider directions for future research.

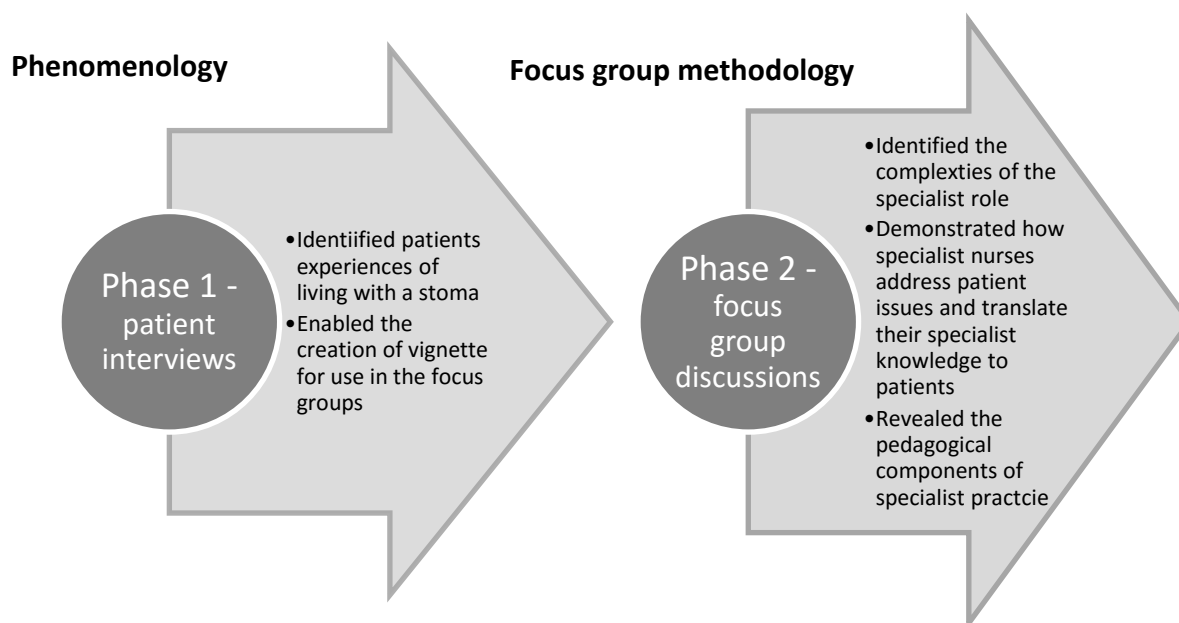
10.2 Critique of the research method

Acknowledgement has already been given to the apparent limited empirical work relating to knowledge translation and subsequent educational needs in specialist nursing practice. This study therefore, has advanced the empirical knowledge in this important area. The aim, the methods of data collection and the strategies for sampling were chosen in an effort to address the gap in the literature. The aim, method of data collection and sampling strategies were deemed unique and chosen in an effort to address the gap in the literature.

A qualitative approach underpinned this two-phase study allowing the aim and objectives to be met. Phase one took an interpretative phenomenological approach and phase two, a focus group methodology. The choice of method for phase one was informed by the aim of affirming a detailed understanding of the patient's experience of living with a stoma.

Vignettes were created from their narratives and used to stimulate discussion by the nurse specialists in the focus groups of phase two. The methodology for phase two was chosen for the sole purpose of eliciting how specialist nurses would address patient issues as disclosed within phase one of the study. The focus group discussions offered the specialist nurses a forum to share their thoughts, feelings, attitudes and ideas; drawing upon both personal experience and professional expertise. It can therefore be concluded that the research design was an appropriate choice for exploring patient experiences and the translation of specialist nurses knowledge and skills.

Figure 10.1 – *Relevance of the research methods to the enquiry*



In both phases, purposive sampling was an appropriate strategy as patients who had experienced living with a stoma and specialist nurses who had cared for patients with a stoma were required to meet the study's objective. The patients represented those people with a variety of diagnoses and stoma types, illness histories and modes of presentation who had recently experienced stoma forming surgery. The nurses represented a group of specialist nurses with a comprehensive array of knowledge and skills, as well as diverse experiences both personally and professionally.

Bracketing within this qualitative approach was acknowledged. Any pre conceived ideas and assumptions have been addressed by the researcher through the use of reflexivity as highlighted in Chapter 9. Bracketing within this qualitative approach was recognised and was felt to be near impossible to 'bracket' prior assumptions and experiences, having worked within the specialty for over 25 years, hence the rationale to choose an interpretative line of inquiry. The use of coding, however, helped the researcher stay

grounded in the data analysis and close to the meanings of the participants. The use of the software package, Nvivo 8, was considered to assist with the data analysis but was found to complicate the process.

10.3 Limitations of the study

Several limitations of this study are identified. Phenomenological studies generally have a small number of participants, only interviewing eight made it difficult to add breadth to some of the themes, in situations where only one participant described different experiences to the others. The recruitment of patient participants proved slow and the lack of insight of the study's aim and objectives, at both recruiting sites may have contributed to this. Recruitment may also have been limited to the uncertainty of disease process and treatment plans. It was noted of the 24 information packs distributed, 10 participant's declined and 6 were deemed unsuitable, for reasons that no stoma had been formed (n=4), early stoma closure had taken place (n=1) and the participant was receiving adjuvant therapies and therefore changed their mind in taking part in the study (n=1).

The various diagnoses of patients should be taken into consideration due to their long term condition. Patients #2, #3, #5, #7 and #8, had all been exposed to the possibilities of a stoma for some time and it could therefore be suggested that they had had some time for preparation, whereas PT#4's adjustment might have been considered more difficult as she had undergone emergency surgery and did not receive standard pre-operative information provided by the specialist stoma care nurse. Patients #1 and #6 had recently been given a diagnosis of cancer. It could be said that they had more pressing concerns such as

questioning their own mortality than to be involved in less trivial matters. Despite these differences, all patients described sharing their stories as having therapeutic benefits (See Chapter 9, Reflection)

The study was only able to provide a 'snapshot' of the reality of the patients' experience of living with a stoma. However, the research method helped to compensate for this. As illustrated in the interview topic guide (See Table 6.2), patients were asked to explore past, present and future experiences of living with a stoma. Contextualisation of these experiences suggests the participants' experiences will continue to develop as they adapt over time. Patients inevitably spoke of their emotional experiences; however as this study has clearly highlighted, not all information is communicated verbally. Whilst nonverbal data was recorded in a journal kept by the researcher, it is likely that some of this communication was lost. Videoing the interviews would have been one solution, and was considered, but this may have inhibited further disclosure of the patients' experiences.

The recruitment of specialist nurses was also disappointing. Fortuitously, another project increased the numbers and pace of specialist nurses recruited. The project was a series of workshop, travelling around the UK. The nature of the road shows reflected similar issues to the study; the researcher was aware that those attending were likely to willingly take part in the study but it could be said the focus group participants already had an interest and desire to explore issues relating to the study. The researcher was known to all the nurse participants in the capacity of Senior Lecturer in Gastrointestinal Nursing, having taught on modules relating to stoma care nursing at both Degree and Masters level. This could have resulted in them feeling obliged to take part in the focus groups and hindered full disclosure

of issues. The presence of an impartial facilitator to chair the focus groups eased these concerns.

The decision to re-examine the phase 2 data through an alternative lens following the 2nd stage analysis resulted in the need to acknowledge the nurse participant's emotional intelligence abilities did not come under scrutiny during the focus group discussions. This said, the researcher also appreciates the consequence of using an emotional intelligence theoretical framework to guide a further analysis of the phase 2 data was likely to reflect such a perspective. Nevertheless, the nurse participants clearly demonstrated the characteristics of emotional intelligence leading to the emergence of the following essential elements to specialist nursing practice.

The scope of this study was limited to specialist stoma care nurses, although there is no suggestion that other specialist nursing areas would reveal different findings, exploring a wider variety of specialist clinical areas would be useful in exploring the wider implications of emotional intelligence in specialist practice.

10.4 Directions for future research

This study has highlighted the challenges faced by patients with a stoma and thus the implications for specialist stoma care nurse education. Analysis of the data indicated the relevance of emotional intelligence in specialist stoma care practice. Since empirical research in this area is found to be limiting, this is the first step in determining whether

there is evidence to support the important role for emotional intelligence in specialist nursing practice.

Potential importance of emotional intelligence to specialist nursing lays in its ability to articulate a form of intelligence that is an integral part of nursing. Emotional intelligence in specialist nursing curriculum warrants further investigation in particular the teaching and learning strategies to explore how competencies in emotional intelligence can be taught. The study is limited to specialist stoma care nursing; therefore further consideration of the wider implications of emotional intelligence to specialist practice is required.

10.5 Conclusion

This study has demonstrated the abilities of specialist stoma care nurses in facilitating patient's adaptation to stoma surgery. It recognises the influences of emotional intelligence, proposing the need for this to be at the heart of specialist nursing educational curricula. This study is unique as it offers insights into patient care, has explored the translation of specialist knowledge and skills and has informed specialist nurse educational curriculum. This work is pivotal in facilitating future research that aims to develop the competent emotionally intelligent specialist nurse practitioner and ultimately improve patient care.

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APPENDIX

APPENDIX 1
(North West Research Ethics Committee
Approval)



National Research Ethics Service

NRES Committee London - Brent

Room 019, Level 7 Maternity Block
Northwick Park Hospital
Watford Road
Harrow
Middlesex
HA1 3UJ

Tel: 020 8869 3805

Fax: 020 8869 5222

21 June 2011

Miss Julia Williams
Lecturer in Gastrointestinal Nursing
Burdett Institute of GI Nursing
St. Mark's Hospital, Watford Road
Harrow, Middlesex
HA1 3UJ

Dear Miss Williams

Study title: Bridging the gap: development of the knowledge and skill of the specialist stoma care nurse to enable the recovery of patients undergoing and having undergone stoma surgery
REC reference: 10/H0717/19

This study was given a favourable ethical opinion by the Committee on 06 April 2010.

It is a condition of approval by the Research Ethics Committee that the Chief Investigator should submit a progress report for the study 12 months after the date on which the favourable opinion was given, and then annually thereafter. To date, the Committee has not yet received the annual progress report for the study, which was due on 05 April 2011. It would be appreciated if you could complete and submit the report by no later than 05 July 2011.

Guidance on progress reports and a copy of the standard NRES progress report form is available from the National Research Ethics Service website.

The NRES website also provides guidance on declaring the end of the study. Failure to submit progress reports may lead to the REC reviewing its opinion on the study.

10/H0717/19:	Please quote this number on all correspondence
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Yours sincerely

Mr Lawrence L. Penez
Committee Co-ordinator

E-mail: lawrence.penez@nhs.net

Copy to: Dr Patricia Grocott, Kings College London, James Clerk Maxwell Building,
Waterloo Campus, London, SE1 8WA.
Dr Alan Warnes, R & D Manager, NWLH NHS Trust

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

APPENDIX 2
(Local Research and Development approval
for Harrow and Oxford)

Ms Julia Williams
Lecturer in Gastrointestinal Nursing
Kings College London
Burdett Institute of GI Nursing
St. Mark's Hospital, Watford Road
Harrow, Middlesex
HA1 3UJ

8th June 2011

Dear Ms Williams

RE: RD10/025: Bridging the gap: development of the knowledge and skills of the specialist stoma care nurse to enable the recovery of patients undergoing and having undergone stoma surgery.

Following your attendance to present your application to the Local Research Ethics Committee on 25th May 2011, I am pleased to confirm the Committee's approval of the above research.

Two SSI forms have been submitted from the R&D office, one of the forms is for Oxford Radcliffe which should be sent directly to them. The Trust cannot give approval for any activities conducted outside the North West London Hospital sites and that you should seek clarification and guidance from the relevant PCT's to ascertain if approval is required from them.

Please also find the attached Code of Conduct, you will need to insert your academic institutions details and print two hard copies and obtain the relevant authorised signatures and turn to this office.

The committee looks forward to receiving an annual report and a copy of your research when it is complete.

Yours sincerely,



Tharani Thurairajah
Research Governance Administrator
NWLH NHS Trust R&D Office
Level 7 Maternity Block, NPH
Tel: 020 8869 2688 Fax 020 8869 5081
research@nwlh.nhs.uk

Ms Julia Williams
Lecturer in Gastrointestinal Nursing
Kings College London
Burdett Institute of GI Nursing
St. Mark's Hospital, Watford Road
Harrow, Middlesex. HA1 3UJ

20th June 2011

Dear Ms Williams

Re: Bridging the gap: development of the knowledge and skills of the specialist stoma care nurse to enable the recovery of patients undergoing and having undergone stoma surgery.

Research and Development Reference: 6177
Research Ethics Committee Reference: 10/H0717/19

Thank you for submitting your application to the Local Research Committee on 25th April 2011. On behalf of the Oxford Radcliffe Hospitals NHS Trust, I am pleased to confirm Trust Management Approval and Indemnity for the above research on the basis described in the application, protocol and other supporting documents.

Your attention is drawn to the attached conditions of approval. Breach of these conditions may result in the Trust Management Approval being revoked. It is noted that King's College London has agreed to undertake responsibility for the study.

Approved Documents

Protocol – V1 – 23/12/09
REC Application and REC Approval letter (with conditions) – 06/04/10
REC Acknowledgement Letter of conditions met – 06/04/10
R&D Application form
Insurance policy
Peer review – 01/02/10
GP letter – V1 – 04/03/10
Patient invite letter – V4 and draft interview topic guide
Specialist Nurse Consent and information form
Signed SSI form
Investigator CV's – Julia Williams, Patricia Grocott

I wish you every success with the study.

Yours sincerely,



Ms Heather House
Research and Development Lead
Research and Development Department
Oxford University Hospitals NHS Trust
Joint Research Office, Block 60, Churchill Hospital
Oxford OX3 7LE
Tel: 01865 572973 Fax: 01865 572242

Cc: Sponsor – Keith Brennan, Kings College London, Academic Supervisor – Dr Patricia Grocott, Kings College London
ORH R&D Dept. Non-CTIMP TMA approval template including conditions of approval

APPENDIX 3
**(Consent forms for patient and specialist
nurse participants)**

(Headed Paper)

PATIENT CONSENT FORM

Bridging the gap: development of the knowledge and skills of the specialist stoma care nurse to enable the recovery of patients undergoing and having undergone stoma surgery.

Centre:.....

Unique Interview Number:.....

Please tick and initial each box

1. I confirm that I have read and understood the information sheet dated..... (version 2) for the above study. I have had the opportunity to consider the information, and ask questions and have had these questions answered satisfactorily

☐

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected

☐

3. I understand that I will be interviewed on 1 occasion (pre-operatively) and this will be tape recorded. Direct quotes from my interview may be used for further research and publication purposes. However I also understand that my identity will not be revealed at any time.

4. I agree to my GP/Consultant Surgeon being informed of my participation in the study

☐

5. I agree to take part in the above study

☐

Name of Patient

Date

Signature

Name of Person taking
Consent

Date

Signature

(When completed, 1 for patient; 1 for GP; 1 for researcher site file)

(Headed paper)

SPECIALIST NURSE CONSENT FORM

Bridging the gap: development of the knowledge and skills of the specialist stoma care nurse to enable the recovery of patients undergoing and having undergone stoma surgery.

Please tick and initial each box

1. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason.

☐

2. I understand that I will be part of a focus group discussion exploring the needs of patients with a stoma. Discussions will be tape recorded and direct quotes may be used for further research and publication purposes. However I understand that my identity will not be revealed at any time

☐

3. I agree to take part in the above study

☐

Name of Nurse Specialist

Date

Signature

Name of Person taking
Consent

Date

Signature

(When completed, 1 for nurse specialist; 1 for researcher site file)

APPENDIX 4

(GP letter)

(Headed paper)

Date

Dear Dr

Your patient of.....

has given their consent to be involved in a research study entitled:

Bridging the gap: development of the knowledge and skills of the specialist stoma care nurse to enable the recovery of patients undergoing and having undergone stoma surgery.

This involves one, one hour interview over the next 4 weeks, with me the researcher.

This study has received ethical approval from the National Research Ethics Committee in Brent in April, 2010 (REC number 10/H0717/19).

If you would like further information to the study please contact me via the details below.

Yours sincerely,

Julia Williams

Senior Lecturer in Gastrointestinal Nursing

The Burdett Institute of Gastrointestinal Nursing in partnership with Kings College London and St. Mark's Hospital, Harrow

0208 869 5431 julia.m.williams@kcl.ac.uk

Included: copy of patient reply slip and consent form

APPENDIX 5
(Patient information pack including reply slip)

(Headed paper)

Date

Dear Patient (Participant)

Bridging the gap: development of the knowledge and skills of the specialist stoma care nurse to enable the recovery of patients undergoing and having undergone stoma surgery.

I am leading a research study exploring people's experiences of having a stoma.

I am currently a Senior Lecturer at the Burdett Institute of Gastrointestinal Nursing in partnership with Kings College London and St Mark's Hospital in Harrow and am undertaking this study as part of my PhD.

The research takes the form of one interview up to 3 months after your surgery and follows your journey up to that point, whilst you adapt to living with a stoma.

For the purposes of this study, two colorectal units recognised for their expertise in stoma care have been chosen, namely St. Mark's Hospital in London and the John Radcliffe Hospital in Oxford, as a means to contact stoma patients who might be interested in participating in this research study.

If you are interested in finding out more about this research and what to do next, an information sheet is enclosed which describes the study and what your participation would involve. Please do not hesitate to contact me if you have any questions about this study.

Thank you for your time.

Yours sincerely,

Julia Williams

Senior Lecturer in Gastrointestinal Nursing

The Burdett Institute of Gastrointestinal Nursing in partnership with Kings College London and St. Mark's Hospital, Harrow

0208 869 5431 julia.m.williams@kcl.ac.uk

(Headed paper)

PATIENT INFORMATION PACK

Bridging the gap: development of the knowledge and skills of the specialist stoma care nurse to enable the recovery of patients undergoing and having undergone stoma surgery.

I would like to invite you to take part in a research study, but before you decide whether or not to take part it is important for you to understand why this research is being undertaken and what it will involve. Please take time to read the following information carefully. You may decide you want to talk to others about the study.

- **PART 1** tells you the purpose of the study and what will happen to you if you take part, and
- **PART 2** gives you more detailed information about the conduct of the study

If you have any further questions or if there is anything not clear, please let me know so that I may clarify them for you. Please take your time in deciding whether or not you wish to take part and return the reply slip indicating your decision.

PART 1

What is the purpose of the study?

The overall purpose of the study is to gain an understanding of the patient experience of having a stoma. In particular the aim is to improve our understanding of the issues people with stomas face as part of their everyday lives. This will allow us to identify ways to ensure they receive appropriate care in the future. For the purposes of this study, two colorectal units recognised for their expertise in stoma care have been chosen, namely St. Mark's Hospital and the John Radcliffe Hospital, Oxford, to contact patients with a stoma who might be interested in participating in this research.

The study is being organized and co-coordinated by myself as part of my PhD studies. About 12 stoma patients will be taking part in the two locations selected.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, please keep this information sheet and sign and return the reply slip enclosed. You will be free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?

Once I have received your reply slip (and you agree to take part), I will contact you to arrange a date to meet with you and explain the study in further detail. With your permission I would like to undertake 1 taped interview, approximately 3 months after your surgery. It is anticipated that the interview will take up to 1 hour to complete as this will allow you discuss your experiences in greater depth. The interview will take place in a convenient location to you; this might be your home or local hospital.

Expenses

Should you incur any travel expenses, I will reimburse you.

What do I have to do?

If you would like to part please complete and return the reply slip in the pre-paid envelope provided, so that I may call you to arrange a date for your interview.

You will be asked to complete a consent form prior to the interview.

What are the possible benefits of taking part?

There is no direct benefit to you but the information we get may help improve the care received to other new stoma patients in the future.

What happens when the research study stops?

The taped interview will be transcribed and then analysed by myself. Your experiences will then be discussed with other specialist stoma care nurses so that preparations can be made to explore how education should be delivered in the future.

What if I have a general stoma problem?

If you have a specific problem with your stoma I will arrange an appointment for you to be seen within two or three days at the stoma care department most local to you.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in PART 2.

Who can I contact for more information about the study?

If you require further information at any point you can contact me, at The Burdett Institute of Gastrointestinal Nursing, on 0208 869 5431 or email me julia.m.williams@kcl.ac.uk

This completes PART 1 of the Information Sheet. If the information in PART 1 has been of interest and you are considering participation, please continue to read the additional information before making any decision.

PART 2**What if there is a problem?**

If there is a problem with something happening during the interview you should let me know immediately during the interview, on 0208 869 5431 or julia.m.williams@kcl.ac.uk

What happens if I have a complaint?

If you have a concern about any aspect of this study you should ask to speak to me as soon as possible. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital where you received your treatment.

Harm

In the unlikely event that something does go wrong and you are harmed during the research there are no special compensation arrangements. If you are harmed and this is due to someone else's negligence then you have grounds for a legal action for compensation against either Oxford Hospitals NHS Trust or North West London Hospitals NHS Trust, but you may have to pay your own legal costs. The normal National Health Service complaints mechanism will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential. No one besides you and me will ever see your transcribed interview. Comments from your interview may be used to illustrate findings in publications and presentations once the research is complete, however, your anonymity will be maintained at all times.

Data from the interviews will be analysed to show the overall findings so that the identity of individuals cannot be identified. The transcribed interviews will be stored securely for 5 years at the Burdett Institute of Gastrointestinal Nursing before being shredded.

Will my GP and Consultant Surgeon be notified that I am taking part?

Yes, however your permission to do so will be sought initially.

Who is organising and funding the research?

I will organize and co-ordinate this study. This is not a commercial study although funding has been sought through several healthcare grant applications and a small grant from the Seed Corn Charity has been awarded.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by Brent Research Ethics Committee.

Thank you very much for your interest. If you decide that you would like to take part please keep this patient information leaflet and sign and return the reply slip in the prepaid envelope provided.

(Headed paper)

REPLY SLIP

Bridging the gap: development of the knowledge and skills of the specialist stoma care nurse to enable the recovery of patients undergoing and having undergone stoma surgery.

Hospital: St. Marks\John Radcliffe (Please delete appropriately)

Yes, I wish to take part in this study, please contact me to arrange a date for my interview ☐ (Please tick)

No, I do not wish to take part in this study, please do not contact me ☐ (Please tick)

MY NAME:.....

ADDRESS:.....

.....

.....

MY CONTACT TELEPHONE NUMBER(S)

.....

Please give any information you would like to add about when best to contact you or when not to contact you

.....

.....

.....

Thank you very much for your interest. If you decide that you would like to take part please keep this patient information leaflet and sign and return the reply slip in the prepaid envelope provided.

(When completed, 1 for GP; 1 for researcher site file)

APPENDIX 6

(Specialist nurse information pack)

(Headed paper)

SPECIALIST NURSE INFORMATION PACK

Bridging the gap: development of the knowledge and skills of the specialist stoma care nurse to enable the recovery of patients undergoing and having undergone stoma surgery.

The purpose of this study is to develop an educational programme for specialist gastrointestinal nurses to equip them in their advanced nursing roles, for benefits of patients. I am undertaking this study as part of my continuing professional development, within a doctoral training programme at Kings College London. This two stage study will initially explore the adult patient's experience of stoma surgery, post-operatively, focusing on adjustment and adaptation. A selection of these experiences will then be offered as feedback to the specialist stoma care nurses for further exploration. This will form the basis for the development of educational programme designed to equip specialist stoma care nurses with the necessary skills to care for this patient group effectively, ultimately improving patient outcomes.

The knowledge and skills of the specialist stoma care nurse will be explored with a particular emphasis towards the adjustment and adaptation a patient undergoes following stoma surgery. This will be done via a series of focus groups. The focus groups will offer the opportunity for the nurses to share their thoughts, feelings, attitudes and ideas towards issues highlighted as important by those patients participating in Phase 1 of the study.

It is anticipated that 8 focus groups will take place over a 7 week period. Up to 8 specialist stoma care nurses will be invited to take part at each of the focus groups. Each focus group will take no longer than 60 minutes and will be facilitated by a co-researcher whilst the principal investigator observes the group's interaction and takes observational field notes.

Each of the focus groups will be tape recorded. The data will be transcribed and analysed according to the themes arising from the data. Through this process your contribution will be anonymised and your identity will not be revealed in discussion with my supervisors, the thesis or any subsequent publications.

If you are interested in being part of this study please complete the reply slip and return to Julia Williams, The Burdett Institute of Gastrointestinal Nursing, c/o St. Mark's Hospital, Watford Road, Harrow, Middlesex. HA1 3UJ or for further information email julia.4.williams@kcl.ac.uk or 0208 869 5431

Thank you very much for your interest. If you decide that you would like to take part please keep this information leaflet and sign the consent